LESSONS LEARNED FROM EVALUATION OF DISABILITY POLICY AND PROGRAMS

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This technical paper on disability is one of the lessons learned series on various social-economic subjects.

1. Introduction

A. Purpose and Organization of This Report

This report summarizes lessons learned about what works or does not work in various disability policy and program areas. It is based on a review of evaluation information from a variety of sources in Canada and several other jurisdictions.

Chapter 2 presents demographic highlights of the disabled population in Canada, identifies the varying ways in which disability has been defined, and discusses the resulting implications for policy and the conduct and interpretation of evaluation.

Chapters 3 through 6 identify what is known about the effectiveness of disability policies and programs as follows:

- Chapter 3 identifies what is known about the potential of people with disabilities to work and the effectiveness of various employment strategies and approaches.

- Chapter 4 discusses the impact of barrier removal legislation in several countries, compares Canadian approaches with those of other countries, such as the *Americans with Disabilities Act*, and identifies the most effective characteristics of different legislative approaches.

- Chapter 5 reviews and discusses approaches to income security, and identifies the dilemma of balancing opportunity and security.

- Chapter 6 discusses the role of personal supports and community-based services in permitting independent living and employment, and identifies the impact and effectiveness of alternative approaches to independent living.

Chapter 7 reviews the current status of evaluation in the area of disability programs and services, and identifies implications for future evaluation approaches.

The scope of this study — essentially evaluations of any policies or programs related to any aspect of disability intervention — is extremely broad. Going beyond consideration of a single type of initiative for a discrete target group, it considers the effectiveness of many different types of initiatives for people with widely ranging needs and characteristics. It takes into account interventions at different levels, ranging from specific programs and services, such as supported employment or attendant care, to broad policy and legislative directions. This breadth of study, the range of initiatives and types of evidence considered, makes a succinct summary a challenging task.

One of the major "lessons learned" arising from the study is the importance of interrelationships and linkages across seemingly distinct policy and program areas. Decisions in any one area can influence effectiveness in others. For example, effectiveness in ensuring employment for the disabled is determined not only by employment and training initiatives, but by the availability of personal supports, transportation and housing, the manner in which income security is provided, taxation and other factors. What is most apparent is the need for a holistic, coordinated approach to disability policy and programs.

B. Context

Taking stock of what is known about what works or does not work in the area of disability programs is particularly timely in the light of recent developments. For example, the federal government has been reconsidering its role in the "new union". Implementation of the new *Employment Insurance Act* provides for a new approach to the manner in which labour market integration will be supported. The federal government has indicated its willingness to "devolve" many employment services to the provinces, and has already entered into some cooperative agreements. Funding for the Vocational Rehabilitation of Disabled Persons (VRDP) Agreement has been extended for another year. During this time, the federal government will be working with the provinces to redesign the program.
In 1996, the Ministers of Human Resources Development, Finance, Justice and National Revenue appointed a Federal Task Force on Disability Issues to address the question: "What is the federal role in the area of disability?" The Task Force report: *Equal Citizenship for Canadians with Disabilities: The Will to Act* (Federal Task Force, 1996) proposed a cross-government disability policy framework and provided 52 recommendations on the themes of citizenship, labour market integration, taxation, income support and legislative reform.

The federal government, in response to the report of the Federal Task Force on Disability Issues, appointed in 1996 by the Ministers of Human Resources Development, Finance, Justice and National Revenue, has indicated its intention to take steps to address inequities, to increase access of people with disabilities to government services and to provide for increased opportunities for participation of disabled people in society. Recently, some action has been taken. The 1997-98 federal budget contained a number of measures taken from the Task Force recommendations. They include the Opportunities Fund of $30 Million per year for three years; broadening the list of expenses eligible for the medical expense tax credit and increasing the limit on part-time attendant care to $10,000; higher limits on the deduction for attendant care expenses; and a new refundable tax credit to cover high medical expenses for low-income working Canadians with disabilities. Minister of Human Resources Development, the Honourable Pierre Pettigrew, has acknowledged his responsibility for disability issues and has indicated that he would be placing priority on improving access by people with disabilities to the services and programs of Human Resources Development Canada (HRDC).

C. Rationale for Federal Involvement in Disability

The starting point of the recent disability debate in Canada is often cited as the 1981 report: *Obstacles: Report of the Special Committee on the Disabled and the Handicapped*. This

report is credited with placing disability issues within a broader framework of human rights and citizenship, rather than as a health, medical or welfare issue. This perspective was officially recognized and formalized the following year, when Section 15 of the *Canadian Charter of Rights and Freedoms* granted persons with mental or physical disabilities the right to equality under the constitution. The *Canadian Human Rights Act* and provincial Human Rights legislation also reflect the principle of equality of access.

In the 1980s, a number of significant events served to focus attention on disability-related issues. In 1983, a Minister Responsible for the Status of Disabled Persons was designated and what is now the Office for Disability Issues was created. That year also marked the beginning of the United Nations Decade of Disabled Persons. The Standing Committee on Human Rights and the Status of Disabled Persons was established in 1987. The committee was instrumental, in 1991, in initiating the National Strategy for the Integration of Persons with Disabilities. The interdepartmental National Strategy was a five-year initiative with the objective of bringing people with disabilities into the social and economic mainstream of Canadian society. Its objectives centred on equal access, economic integration and effective participation of people with disabilities.

According to Statistics Canada, there were 4.2 million Canadians with disabilities in 1991, up from 3.3 million in 1986, an increase associated with an aging population. This represents 15.5 per cent of Canada's population. Disabilities cut across gender, age groups and social groups, although the rate of disability among Aboriginal people is twice that of non-Native Canadians. Some 60 per cent of people with disabilities live below the poverty level in Canada. While the full costs of disability to society are not known, the estimated cost to the federal government of income support programs and provision of goods and services is more than $6 billion annually. This does not take into account the costs of provincial programs and private sector insurance plans, or the lost income and foregone taxes from people who are capable of work but who face barriers which prevent them from employment.

Disability-related issues in Canada are a shared responsibility. While many programs within the federal government specifically aimed at people with disabilities have now been consolidated under HRDC, activities and programs across all federal departments can have a bearing on people with disabilities. Because of the inter-relationships across diverse program areas, a number of reviews, ranging from *Obstacles* to the most recent Task Force report, have identified the need for a coordinated government vision and action. Disability-related issues are also a shared responsibility between the federal and provincial/territorial governments. Still, the principles of inclusiveness implied in Canadian citizenship and obligations under the constitution to ensure equity in the use of funds give the federal government a base to promote its commitments to equality contained in international and national instruments that underpin full citizenship.

On the international front, there has been comparable recognition of the right of people with disabilities to inclusion and equality, and the responsibilities of governments to remove barriers which prevent people with disabilities from being able to exercise their right to participate fully in the activities of their societies. The UN *Standard Rules on the*

Equalization of Opportunities for Persons with Disabilities (United Nations, 1994) provide principles for policies and action by governments to enable people with disabilities to be able to exercise the same rights and obligations as others. Canada is a signatory to the *Standard Rules* and played a lead role in their development. The stated objectives of most western nations have shifted away from a paternalistic approach to providing services to people deemed not capable of participating in the mainstream of society, towards policies that encourage and facilitate independence and responsibility (Lunt and Thornton, 1993).

In summary, this report suggests there are two basic goals for government policy regarding disability. These can also be viewed as broad "success" criteria to be used in assessing the effectiveness and impact of policies and programs. They thus set the context and basis for evaluation.

- **Equality and Full Participation.** As discussed above, various government reviews, consistent with international developments, identify the right of people with disabilities to inclusion and full participation in society. They state that the objective of government policies and programs should be to remove barriers which make this impossible. The provision of special programs and supports is consistent with this objective, indeed is a central corollary.

- **Cost Effectiveness.** There is general recognition that all public programs and services must be provided as cost-effectively as possible. Given the limited direct government funding available for social programs, it would be helpful to government, to provider agencies, and to people with disabilities to be able to identify the types of programs and services that provide the greatest value.

Services for people with disabilities are frequently looked at as a cost with no compensating financial benefits. Another perspective recognizes the significant cost, to society and the taxpayer as well as to the individual, of maintaining the status quo. Complicating the issue is the fact that cost savings resulting from disability initiatives may appear in different budget or program areas from those where funds are expended, and may occur over a prolonged period of time. Better information about the financial benefits of programs and services for people with disabilities can aid in the development and implementation of future policies and program directions.

D. Scope, Methodology and Focus of This Paper

This study provides an overview, indicating the general state-of-the-art regarding the broad area of disability policy. It is based on a review of existing documentation from a number of different jurisdictions and information bases around the world. It attempts to identify policy-level evaluations to the extent possible. Some of the information identified consists of formal evaluation studies and needs assessments. Other sources of information may be more descriptive in nature. Also examined are a number of reviews in various areas.

Contacts in Canada and in a number of other countries were used to help identify and obtain documentation, and also in some cases to help assess if there were any gaps in what had been identified. A variety of literature searches were also carried out and the Internet was used to identify and obtain a number of documents.

There has been an increasing amount of evaluation and research in several jurisdictions exploring the effectiveness of various approaches and strategies and on different topic areas. As this study shows, there *is* considerable evaluation and research information about what makes for effective programs and policies in the disability area. Indeed, there *are* many good examples of "success" — from Canada and from other jurisdictions. But this information needs to be identified and consolidated in a way that is useful to the policy development process.

The Bibliography lists the sources of information identified. The study does not cite each of these sources in the text.

The scope of this study is very broad, identifying major themes and giving a sense of the evaluation activity that has been done or is under way. The time available for information gathering was quite limited; consequently the search for information, while extensive, was not exhaustive. It was not possible to examine every identified study in detail. In general, a cross-disability perspective was adopted, with limited attention to literature about specific disability groups.

The documentation reviewed considered a wide variety of different types of individuals, programs and policies. These ranged from broad policy overviews to evaluation of program approaches in very specific contexts. For these reasons, a formal evaluation synthesis was not appropriate.

Despite these limitations, the study presents a fair overview of the major themes and "lessons learned" about the effectiveness of interventions related to disability. This information has many important implications for the development and implementation of policies regarding people with disabilities.

2. Major Characteristics of the Disabled Population and Definitions of Disability in Canada

A. Demographic Highlights and Implications

Statistics Canada carried out two post-censal disability surveys, in 1986 and 1991, entitled Health and Activity Limitations Surveys (HALS). Findings from the most recent HALS have been reported in several sources, including Statistics Canada publications, the Social Security Reform Supplementary Paper on Persons with Disabilities (HRDC, 1994), statistics compiled by the Office for Disability Issues, and most recently, Fawcett's (1996) book commissioned by HRDC which looks specifically at the economic characteristics of Canadians with disabilities. The master file of the Labour Market Activity Survey (LMAS) also contains data on the relationship between disability and labour market activity.

Some highlights from the most recent HALS have particular implications for this study.

- In 1991, 4.2 million Canadians, 15.5 per cent of the population, have a disability - an increase from 1986, when the number of people with a disability was 3.3 million, or 13.2 per cent of the population.

- Prevalence of disability is closely related to age, with the disability rate ranging from 7 per cent of children under age 14 to 50 per cent of those over age 65. The rate of disability for working age Canadians, aged 15 to 64, is 13 per cent.

- Working age Canadians (age 15 to 64) number 2.3 million, or 59 per cent.

- People with disabilities are much more likely to live in poverty than other Canadians. Of adults with disabilities, 43 per cent had an individual income of less than $10,000 per year and 26 per cent had income of less than $5,000. Adults with severe disabilities are much more likely to be poor than those with mild disabilities. These figures do not take into account the extraordinary costs associated with disability, which can be substantial in many situations (see, for example, Federal Task Force, 1996; Perrin, 1991; Roeher Institute, 1994a).

- In 1991, 48 per cent of working-age people with disabilities were employed, 8 per cent unemployed, and 44 per cent "not in the labour force." People with severe disabilities are least likely to be in the labour force. Nonetheless, 26 per cent of this group do participate, despite severe disabilities.

Adults with disabilities have lower education levels than adults without disabilities. For example, HALS found that for 65 per cent of disabled people, the highest level of education

was high school or less (compared to 50 per cent for others); 6 per cent of adults with disabilities had a university degree (14 per cent for others).

For adults with disabilities, education appears to be at least as important for employment as it is for others. Data from HALS (HRDC, 1994) indicate that the employment rate of adults with disabilities with university education (67 per cent) is more than double that for those with elementary school education (30 per cent). The comparable figures for adults without disabilities are 87 per cent and 53 per cent. As Fawcett (1996) indicates, in spite of the effectiveness of education in increasing the labour force participation (and employment) of persons with disabilities, rates of participation and employment are considerably less than for people without disabilities at comparable levels of education.

There are, however, some encouraging signs. Levels of education of people with disabilities has increased from 1986 to 1991. The increase appears to be among young people. Nevertheless, the 1991 HALS survey (HRDC, 1994) still found that the highest level of schooling completed by youth (aged 15 to 24) with disabilities is lower than for youth without disabilities. The education levels of young women, both with and without disabilities, are somewhat higher than for young men.

Hum and Simpson (1996) used the master file of the LMAS to investigate the effect of disability on labour market activity. As they point out, HALS gives little data on labour market activities, while the LAMS is a rich source of data. They used multivariate regression analyses in order to identify the impact of various factors that influence the labour market activity of Canadians with and without disabilities. In their analyses, they found "evidence of a higher return to education for persons with disabilities who remain employed than for comparable workers without disabilities." They interpret these results cautiously, however, as they did not incorporate men and women who are not employed in the sample. They suggest that this is an area for future research using the LMAS master file.

HALS, and other data sources indicate that the disabled population in Canada is heterogeneous. People with disabilities do not form a unified group with common characteristics. They are just as diverse as the rest of the population, for example, in terms of

- age variation
- gender
- living arrangements
- geographic location and community size and type
- occupation
- income
- cultural/racial background
- attitudes and capabilities
- interests.

Disability-related characteristics also vary widely. There are a number of very different types of disability. As noted earlier, the severity of disability varies from person to person.

Disability can affect people in different ways. Even people with the "same" disability may be affected differently by it, and have differing needs and require differing forms of supports and accommodations.

Some disabilities are present at birth, while others develop later in life — even for the "same" disability (visual impairment, for example). The stage at which a disability develops can sometimes have significant implications for the types of supports an individual needs. Some disabilities are permanent, with their impact continuous. But others may have periodic impact. This can be true not only for certain types of disabilities - manic depressiveness, for example - but in situations where the severity of the disability varies over time, or even day to day. People with muscular weakness, for example, may need to use a wheelchair some but not all of the time.

Some disabilities, such as multiple sclerosis, can be progressive, so that the nature and severity of the disability, and how it affects the individual, can vary over the course of time. While the term disability usually refers to a long-term condition (HALS requires the disability to endure for at least six months), some disabilities are temporary in nature, particularly many of the mild disabilities.

Indeed, a major finding of Fawcett (1996) is that disability is not a static state, that a surprising number of people with disabilities experience significant changes in their disabled status from year to year. She points out that despite the fairly constant overall rate of disability in the total population from year to year, use of longitudinal data from the LMAS indicates that there is significant turnover in disability status among individuals. In addition, environmental changes - such as changes in family responsibilities and life circumstances, attitudes of employers, availability of special programs or accessibility aids - can make greater or lesser labour force involvement possible.

Discussion

A large portion of the Canadian population — 4.2 million people or 15.5 per cent in 1991 — have a disability. That is not an insignificant number (in Europe, the disabled have been described as the largest minority group).

Moreover, with an aging population, the number of people with disabilities in Canada is expected to increase. The "baby boomers" represent the largest demographic cohort of the overall population. This cohort is starting to enter middle age. Over the medium term, the increase in the *numbers* of people who can be expected to develop a disability will be greatest among working-age Canadians. This will have significant financial and social implications -- unless ways are developed to assist people with disabilities to continue to participate in the labour market and in society.

As noted above, education is at least as important to employment success for people with disabilities as it is for others. The changing nature of work, along with advances in

technology, *may* present opportunities for people with disabilities (see Samorodov, 1996). The availability of affordable technology can make it easier to accommodate the special needs of many people with disabilities. Increasing flexibility at the workplace, such as increasing use of flexible work hours and work-at-home practices, may also make it easier for some people with disabilities to be employed.

But it is not at all clear that a labour market in constant change will be to the advantage of people with disabilities. In particular, the increasing demands for higher-level skills as well as other factors may increase the employment disadvantage faced by people with disabilities with limited levels of education. This is a likely area for useful research in identifying the potential impact of the "new economy" on the employment prospects of people with disabilities.

Education is not a direct federal responsibility. Nevertheless, there may be opportunities to make better use of existing vehicles, such as federal support for post-secondary education, literacy, and support for youth, to assist people with disabilities in improving their education.

The heterogeneity of the disabled population also has important implications for both policy and evaluation. As Hum and Simpson (1996) state, based on their analysis of Canadians with disabilities and the labour market:

> "Simply identifying those with disabilities is inadequate, since this is too heterogeneous a group. An attempt to aid all Canadians with disabilities, regardless of the degree of severity, may give rise to misleading or disappointing results."

A limitation of the data presented in this chapter is that they are now more than six years old. They precede the current economic downturn, as well as the recent reductions in social services at all levels. It is therefore probable that the current economic and employment situation of people with disabilities is less positive than the data indicate.

Data such as those provided by HALS seem to be a basic prerequisite in order to be able to monitor the impact of disability policy. Unfortunately, this post-censal disability survey has been discontinued. Hum and Simpson (1996), as well as Fawcett (1996) to some extent, were able to use the master file of the LMAS, despite some limitations, to examine the impact of disability on labour market activity, because a supplement on disability in 1989 and 1990 was attached to this longitudinal survey. The LMAS itself was discontinued in 1990.

It would seem desirable to reinstate HALS, or a similar vehicle for obtaining basic information about people with disabilities, even if on a more modest scale. Indeed, obtaining more timely information, no more than one to two years old, would be much more useful in assessing the impact of disability policies. This might be a subject for discussion between HRDC and Statistics Canada.

B. Definitions of Disability

Defining disability, and determining if someone has a disability, may seem straightforward. The evidence, however, indicates that it is not. The literature shows that there are various ways of defining and identifying disability. How it is done can result in differing characterizations of the disabled population and differing conceptions of disability. This in turn can have important implications for both policy and evaluation.

For example, Lunt and Thornton (1993) point out that definitions of disability are used for a variety of different purposes. They indicate that disability is often defined to be as inclusive as possible, such as in overarching legislation, while in other cases, definitions are used to control access and to ration services. They point out that there is a tension between these non-restrictive and inclusive definitions.

A number of commentators and reviews (European Day of Disabled Persons Secretariat, 1996; Mainstream 1992; Oliver, 1990; Pfeiffer, 1995; Rioux and Bach, 1994) have indicated how the manner in which disability is determined reflects philosophical orientations as to how disability is viewed — and dealt with. They show how the traditional, medical approach to defining disability reflects the medical model approach to the "treatment" of disability. Medical definitions, which view people with disabilities as a special class of "ill" people, do not take into account the consequences of an impairment for an individual in terms of being able to function. This has led to functional definitions, such as those used by HALS, based on an individual's ability to perform activities of daily living. Disability is also sometimes defined partly in vocational terms ("permanently unemployable", for example).

Some commentators (Lunt and Thornton, 1993; Pfeiffer, 1995) have indicated that medical and functional definitions of disability emphasize incapacity rather than the capacity of people. The European Commission (1996b) argues that these definitions lead to disability being viewed simply as a problem that an individual has, failing to recognize that:

> "The term 'disability' represents a complex system of social restrictions. For example, wheelchair users are denied opportunities because the places they wish or need to travel to and from are inaccessible. Visually impaired people are denied opportunities simply because ways to interact fully with the world by non-visual means are not made available to them. Persons with learning difficulties may fail to learn a task which they have the potential to perform because the appropriate training techniques required to assist them are not available."

The Mainstream 1992 report shows how the way in which disability is viewed and defined has been evolving from a "warehouse" to "greenhouse" to an "open house" perspective. While the exact terminology varies, the concepts are the same as others use in describing the evolution from a medical to a functional to a socio-political model of disability (Oliver, 1990; Rioux and Bach, 1994).

The definition of disability developed by the World Health Organization in 1980 is gaining increasing acceptance. The WHO definition recognizes multiple levels:

- Impairment — a physiological, anatomical or psychological loss or abnormality of function (e.g., deafness, paraplegia).

- Disability -- a restriction of functional ability and activity caused by an impairment (e.g., loss of hearing, reduced mobility).

- Handicap — A social or environmental disadvantage resulting from impairment or disability (e.g., communication, access to buildings).

Implicit in the WHO definition is the concept that an impairment need not lead to a disability, and a disability need not result in a handicap. A handicap results from the interaction between the characteristics of the individual and the environment. As Hollander (1993) stated:

> "A disability is not a characteristic of a person but a relationship between the person and the environment. A disability is relative in this sense. This is important because it places the responsibility on the environment rather than on the person."

The WHO conception of disability is being recognized in legislation (Sweden, the United States) and policy (province of Québec, European Union) in an increasing number of jurisdictions. Indeed, it is reflected in Canada's constitution, given the interpretations of Section 15 by the Supreme Court citing the failure of society to make reasonable accommodations, to fine-tune its structures so that they do not result in discrimination against people with disabilities.

The WHO model of disability has been subject to considerably further refinement and specification, such as the International Classification of Impairments, Disabilities, and Handicaps. While there is agreement with the general approach, some of this work has been subject to criticism (Pfeiffer, 1995) for being overly medically oriented, for focusing on characteristics of the individual rather than those of society which produces the handicap, and for devaluing the quality of life of people with disabilities.

The report of the Social Security Review regarding Persons with Disabilities (HRDC, 1994) argues that determining eligibility for programs or benefits should be a different matter from clearly defining the target population. However, the report points out that:

> "A common failing is to confuse the definition of disability with the eligibility criteria. It is important to remember that it is acceptable for different programs to have different objectives. However, it is not the definition of disability that should change from one program to another, but rather the eligibility criteria."

This report further asserts that: "In Canada, the tendency has been to define disability on the basis of the intentions of programs." Thus eligibility criteria often act as *de facto* operational definitions. Despite support in principle for the WHO definition of disability, programs in Canada tend to define eligibility in terms of a combination of medical, functional and vocational criteria, often also taking into account the cause of the disability and the circumstances under which it occurred - at the workplace, in an automobile accident, and so forth.

Discussion

As noted above, the manner in which disability is defined has implications for how people with disabilities are viewed and treated. This in turn has important implications for the design and development of policy and program approaches.

For example, the WHO definition of disability, which emphasizes the interaction between the individual and the environment rather than the limitations or characteristics of the individual, suggests that program and policy focus should be on exploring ways of modifying societal barriers in order to be able to accommodate people with their differences. This is clearly the direction identified in Canada in major reviews such as the Task Force report and the Mainstream 1992 review, as well as by new directions in other countries. It is, however, is a different focus than that suggested by medical and functional definitions of disability, which suggest a focus on modifying or adapting individuals.

The "environmental" (as opposed to "functional") model of disability definition also has significant implications for the focus of evaluation studies and the interpretation of their findings. It suggests that evaluation studies should consider the extent to which programs and policies attempt to accommodate the needs of people with disabilities and the degree of their success in doing so. For example, evaluation of employment programs, rather than considering the capacity or incapacity of individuals with disabilities to work, should identify barriers to employment, what circumstances or supports could overcome them, and the extent to which these were applied and were effective.

It is, of course, quite appropriate for different programs to have different objectives and eligibility requirements. But the confusion of eligibility requirements with definitions, and the lack of consistency in the way disability is defined can make comparisons across programs difficult or impossible. This has implications for the design and conduct of evaluation studies, and suggests caution in interpreting data obtained from across different programs.

To illustrate, the use of different definitions can result in major differences in factors such as the size, characteristics and needs of the disabled population or sub-populations. Definitions can affect eligibility for services and characteristics of clients. Program impact can be skewed by the definitions used. For example, as the Canadian Human Rights Commission has indicated, relaxed definitions of disability have been used by some organizations to make their figures appear more positive for Employment Equity reporting requirements.

Definitions are not neutral. They have major impacts on how people with disabilities are viewed and treated. They have implications for how programs and policies are provided. The manner in which disability is defined can open up opportunities — or can limit them. Definitions provide a context for asking appropriate evaluation questions about the effectiveness of programs and policies.

C. Diversity of Disability Programs and Services

However one defines disability, it is clear from HALS and other sources that the disabled population in Canada is very diverse. People with disabilities, by and large, have more in common with the general population than with each other.

Given the size and diversity of the disabled population in Canada, it is neither surprising nor unexpected that there is a wide range of policies and program areas, as well as services and fields of study, related to disability. There are policies and services related to some aspect of disability at all levels, from the national to community levels, involving government, the community and private sectors. Some policies and programs may affect everyone, whereas others may be very specific depending upon the nature of the disability and a myriad of other factors.

There is a wide variety of specific disability-related services, dealing with a range of needs such as housing, personal supports, transportation, medical or vocational rehabilitation, family services, and so forth. Some services are provided on a cross-disability basis, but many are directed at people with specific types of disabilities or impairments. Services can be very specialized. For example, they may be directed as very specific types of disabilities, such as specialized services for children with Down's Syndrome, or separate programs for blind and low vision people. Supported employment programs may be developed for people with intellectual disabilities, with very specific needs or characteristics.

Disability services in Canada are most likely to be provided by community-based agencies (Except, of course, for income support programs, which are provided by various government agencies, or private insurers in certain circumstances). Some agencies may provide a variety of different services, some only a single type. Organizations providing disability-related services operate within a range of different philosophies about disability. For example, there is an increasing number of programs designed to enable individuals to make their own choices about their service needs. But there are still many programs that are professionally driven, as well as programs based on models of segregation rather than integration.

There are also many different fields of study and activity examining sometimes quite specific aspects of disability. Dozens of academic disciplines may relate to disability in some way. Each of these interests has its own body of information, its own experts, its own set of beliefs and dissemination channels.

Thus the disability "system", in Canada as elsewhere, can be categorized as a fragmented collection of parts. There is often a lack of coordination. This is a major theme in many different reviews and critiques of the disability area in Canada.

People with disabilities also use the same regular programs and services that serve the general population. These include, for example, regular policies, programs and services regarding employment, education and training, transportation, housing, leisure and recreation, community-based services, and many others. "Generic" programs and services can influence the quality of life of people with disabilities more than specialized services. How regular services are structured will influence the extent to which they can be used by people with disabilities on the same basis as others - for example the extent to which they take into account potential barriers to people with disabilities. Disability-specific services are often needed only when regular programs are unable or unwilling to accommodate people with disabilities.

As indicated, for example, by the Mainstream 1992 Review, the focus has been shifting from provision of specialized services for people with disabilities to the use of mainstream services, programs, and facilities. The role of specialized services is changing, away from the provision of parallel or segregated services, towards the provision of support, facilitation and advocacy to assist the disabled to use regular services, and towards assisting these services to accommodate people with disabilities. This movement has significant implications for the development and evaluation of policy.

Given the diversity of the policies and services and fields of study related to disability, it may be inappropriate to speak of ***the*** disability area. The diversity and heterogeneity has implications for policy and for how evaluation is carried out. At the very least, this diversity needs to be taken into account. Various parliamentary and other reviews have indicated how the complexity of the disability area can lead to gaps and overlaps and people falling between the cracks. This suggests that a systems approach in the design of policies, and in evaluating effectiveness, might be helpful.

D. Summary: Major Findings and Lessons Learned

- People with disabilities constitute a sizable proportion of the Canadian population. Demographic changes will result in increasing numbers of people with disabilities in Canada, particularly among people of working age. Level of education is at least as important in enabling people with disabilities to obtain employment as it is for others.

- Needs of people with disabilities are not uniform. The disability area consists of a wide range of largely uncoordinated services and components. The heterogeneity, diversity and complexity of disability area needs to be taken into account in the development and evaluation of policies that can affect people with disabilities.

- Disability is defined in a variety of ways, which are often confused with eligibility criteria for programs. This can make comparability across different programs difficult or impossible, and needs to be taken into account in the design of evaluation studies and in the interpretation of findings.

- The most commonly accepted definition of disability, from the World Health Organization, recognizes disability as involving an interaction between the individual and the environment. This definition acknowledges that an individual's ability to function in society and to be employed, for example, depends as much on the openness of society to accommodate people with their differences, as it does on the specific functional limitations of individuals identified as "disabled". This principle has important implications for the development of policies and for the focus of evaluations.

3. Employment: What Approaches Enable People with Disabilities to Work?

A. The Potential of People with Disabilities to Work

As Fawcett (1996) states: "There is a common misconception that persons with disabilities who are not in the labour force are either unable or unwilling to work. . . . There is ample evidence to suggest, however, that neither perception accurately characterizes this population."

True, not *all* people with disabilities are ready and able to work. Employment may be difficult, painful or impossible for some people part or all of the time. Income support, as discussed in the following chapter, is a necessity for these people. Both internal and external barriers, such as competencies, education, work and social skills, lack of experience and exposure to the working world, and others may make work difficult. There is evidence that many of these barriers, while challenging, are not insurmountable.

But there is considerable evidence that a substantial proportion of the disability population not currently employed *is* capable of at least some form of work under the right circumstances.

The HALS data contain evidence of the willingness and ability to work of people with disabilities who are not in the labour force. Fawcett (1996) developed a composite measure of work potential which showed that 31 per cent of people with disabilities who were out of the labour force displayed one or more indicators of work potential. Fawcett describes this as an instance of "hidden unemployed." These indicators of work potential include people who:

- are active in volunteer or unpaid work;
- are students, whose status indicates that they are not out of the labour force due to an inability or unwillingness to work for pay, but because they are still preparing for work;
- express the intention to look for work within six months;
- have not worked for pay in at least five years, but have looked for work within the last two years;
- looked for work within the past five years but have been turned down because of their disability.

Fawcett also combined HALS data, which showed that 44 per cent of people with disabilities who were not in the paid labour force identified at least one environmental barrier or personal circumstance which prevented them from working. Examples of barriers identified include: fear of losing income support or disability benefits (such as assistive devices, subsidized medication) if they looked for work, or fear of difficulty in re-establishing benefits if the job did not

work out; discouragement by family or others from seeking paid work; lack of access to job information; inadequate training; past discrimination in the labour force; worry about being isolated on the job due to disability; feeling that there were no jobs available; lack of accessible transportation.

Fawcett (1996) concluded:

> "Overall, 56 per cent of persons with disabilities who were out of the paid labour force showed signs of future work potential or indicated that at least one environmental barrier kept them from looking for work. . . . This means that if circumstances (other than the disability itself) had changed, more than half of the persons with disabilities who were out of the labour force would have been likely candidates for paid employment."

Fawcett also points out that a surprising number of people with disabilities experience changes in their disability status from one year to the next. Thus many people who may not be able to work at any given time due to disability may be able to work at a later date.

There is considerable evidence from many other sources documenting the potential for a substantial proportion of people with disabilities who are not in the labour force to be employed. For example, while most people with severe disabilities are not in the labour force, a significant proportion (26 per cent in 1991) were. Why are some, but not other, people with severe disabilities able to obtain work?

The Roeher Institute *On Target (1992)* study, drawing upon HALS data and other sources of information, found that *unavailability of accommodations and supports is a bigger barrier to employment than severity of disability.* The three types accommodations most often identified by people with disabilities not in the labour force as required to enable them to work are: modified or reduced hours (33 per cent), job redesign (27 per cent), and accessible transportation (14 per cent).

There are many examples in the literature illustrating the potential of individuals with severe disabilities, given appropriate supports, to work. For example, an evaluation sponsored by the United States Department of Health and Human services and the United States Department of Labor (Conley, Azzam and Mitchell, 1995) examined a number of projects that attempted to assist students with very severe disabilities (mainly "severe mental retardation", many with multiple disabilities) to obtain integrated employment using natural supports. The intention of the project, confirmed by the evaluation, was to select people with the most severe disabilities. In the absence of these projects, almost all of these students would have been placed in traditional sheltered employment or workshops.

This evaluation concluded:

> "Severity of disability is usually not an insurmountable barrier. Although there are obvious instances of persons whose disability is so severe that there is little

possibility of vocational success, the projects have shown that integrated employment with natural supports is a realistic goal for most people who are currently placed in segregated employment sites [and similar alternatives]."

Nevertheless, this evaluation stated that "the fact that such employment is possible, however, does not mean that it is easily obtained." The evaluation identified some of these barriers and how projects were able to deal with them. For example, most employers indicated a strong need for substantial up-front assistance when employing people with severe disabilities. While increased costs were viewed by employers as relatively minor, most employers were heavily supported by publicly funded sources in dealing with inappropriate behaviours, training and other considerations. The evaluation identified this support as a key ingredient to the success of the project.

The evaluation acknowledged that this type of project requires additional up-front costs. It noted, however, that unlike more traditional approaches such as sheltered employment or workshops, costs would be offset in many (but not all) cases by subsequent savings.

As discussed in Section 3.F, supported employment programs similarly work with people with severe disabilities, enabling people to work with supports who otherwise would not be able to do so. Various supported employment programs have identified the potential of people with severe disabilities and limitations to do productive work.

The Neil Squire Foundation operates a Creative Employment Options program, which trains individuals with severe physical disabilities. A large proportion of program participants, most of whom were unemployed for a long time without prospects before entering the program, found competitive employment upon graduation. The Foundation (Birch, 1996) has carried out a preliminary calculation of economic benefits arising from participation in the program, based on savings in social assistance spending and taxes paid to government. These preliminary calculations suggest a return on investment to government of better than six to one.

Discussion

There is strong evidence that a substantial proportion of people with disabilities who are not currently in the labour force are capable of being employed in some way, given the proper supports and the removal of barriers that now make it impossible. The evidence provides support for the inter-relatedness of disability issues. It suggests that approaches that focus only on employment and do not address other barriers may be limited in effectiveness. The relationship between success in employment with the availability of other services is discussed further in Section 3.G.

Many people with disabilities, given the right work environment and removal of barriers, are capable of working on the same basis as anyone else. For others, particularly with severe disabilities and lack of skills, regular, full time employment may be challenging. But they may still be capable of doing *some* work. For example, most of the participants in the projects

evaluated by the Conley et al. (1995) study worked less than half time. This may not be sufficient to generate a subsistence income, but given the right income support policies, can more than cover the costs of the necessary supports and result in a number of other social and economic benefits as well.

Showing that it is possible for people with severe disabilities to work does not mean that it is easy. The evidence indicates that the severely disabled face many barriers. Successful interventions may require significant up-front costs, although there is potential for longer term savings. In addition, it should also be noted that labour market demand plays a significant role in determining their employment opportunities.

The evidence also suggests the need to get away from thinking in terms of the employability of people with disabilities as a yes/no dichotomy. Many people, in particular those with very severe disabilities, may be limited in the *amount* of work they are able to do. Some people may not be capable of fully productive work, but can still do something, given the proper supports. Many people currently excluded from the labour force may be capable of earning some income through employment, even though this may be less than what they are currently receiving through various income support schemes.

As Chapter 5 indicates, the all-or-nothing concept of employability incorporated into eligibility requirements of disability income systems such as the Canada Pension Plan acts as a powerful disincentive for people receiving social benefits to search for or to accept employment. The GAO (1996h) stated that:

> "The either/or nature of the disability determination process encourages applicants to focus on their inabilities. The documentation involved in establishing one's disability can, many believe, create a 'disability mind set' that erodes motivation to work, and the length of time required to determine eligibility can weaken skills, abilities, and habits necessary to work."

The Mainstream 1992 review, Parliamentary Standing Committee reports, and other sources document that greater opportunities for employment as a major interest of the disabled community. They identify exclusion from the labour force as one of the leading sources of frustration among people with disabilities.

B. Disability Management and Return to Work

Disability management refers to the active follow-up and management of employees who are off work due to work-related or non-work-related disabilities and injuries. It typically involves providing case management services and the availability of individualized, outcome-oriented rehabilitation services, taking into account the individual's interests and abilities. The type and intensity of services and supports vary depending upon the individuals' needs and what would enable them to return to work.

One aspect of disability management involves the individual in learning how to address functional limitations resulting from the disability. But another aspect focuses on the workplace, identifying what accommodations are needed to permit return to work. These may include, for example, redesign of the work site in some way, flexible or variable work hours, or assignment to a different job within the individual's capabilities.

Disability management strategies have been used in various countries, including Canada, the United States and Europe, in both the private and public sectors. There is strong evaluation evidence showing their potential to enable individuals to return to work and to create significant cost savings. Perhaps as a result, these strategies are becoming more widespread.

The Canadian federal government recently completed a disability management pilot project involving provision of case management services in three federal departments. An independent evaluation (Insight Canada, 1996) of the pilot project indicated that this approach represented "a major departure from traditional *laissez-faire* federal practices in the area of helping injured and disabled workers return to work." The evaluation identified the success of the project in enabling individuals to return to work sooner than they would have otherwise. It also identified major cost savings, and a return on investment for the project costs of 63 to 1 (cost savings resulted from actual and expected reductions in Disability Income, Long-Term Disability, and Workers' Compensation benefits). Significantly, there were even greater savings among employees whose disability was not work related than for those who were injured on the job.

The evaluation pointed out that it can sometimes be difficult to determine with any certainty how many people might return to work without intervention. But it notes that in at least one of the participating departments, virtually all the employees had been away from work for a long time.

The evaluation also identified a number of barriers. One major barrier is the lack of understanding among senior managers of the real costs of paying for workers who are absent due to injuries or disabilities. There is also lack of accountability for results, as the costs are incurred elsewhere in government. For these and other reasons - such as lack of interest in people with disabilities or lack of belief in their capability to be re-employed - the evaluation documented resistance to disability management among human resources departments as well as by senior management. This resistance impaired operation of the program in some instances, hampering early intervention in particular, because of lack of timely access to the names of people at an early stage. The evaluation recommended the development of an accountability framework in order to provide incentives.

The federal government experience reflects that of the private sector, where major cost savings have been found through proactive return-to-work strategies (Boxer, Young, and Kirchner, 1994; GAO, 1996i; Prost, 1996; Washington Business Group on Health, 1994). Private sector return-to-work efforts are becoming more commonplace. GAO (1996i) indicated that:

> "Disability managers in the U.S. private sector spend money on return-to-work efforts because they believe such efforts are sound investments that reduce disability-related costs. Studies have estimated that the full cost of disability to employers ranges from about 6 to 12 per cent of payroll. Such costs include insurance premiums, cash benefits, rehabilitation benefits, and medical benefits paid through workers' compensation and employer-sponsored disability insurance programs. Companies may also incur additional expenses for training and using temporary workers and retraining employees with disabilities when they return to work. When businesses help workers with disabilities return to the workplace, they are able to reduce some of these costs."

Extensive research (Allingham and Hyatt, 1995; Butler, Johnson, and Baldwin, 1995; Johnson and Baldwin, 1993) using the Ontario WCB database has explored in detail the impact of vocational rehabilitation on the return to work of workers with permanent partial disabilities. This research has demonstrated the effectiveness of rehabilitation in fostering return to work. It points out, however, that the first return to work is not always an indication of permanency. It emphasizes the importance of the interaction between employer and employee and the need for accommodations to permit workers to be re-employed.

The need to view disability management as an ongoing versus a one-time process was reinforced in an evaluation of job accommodations sponsored by HRDC (Perrin, 1995). This study showed that accommodation needs can change over time for a variety of reasons including changes in the nature of the disability itself, changes in the requirements of the job as well as actual job positions, and aids and adaptations becoming out of date as a result of things like changes in technology.

Many WCB claimants have what might be considered relatively minor or temporal disabilities resulting from workplace injuries (although they are severe enough to keep people from being able to work, and as the research cited above indicates, they can make work re-entry difficult or impossible without workplace accommodations and other supports). But the same finding has been found for people with traumatic injuries. For example, Abrams, Barker, Haffey and Nelson (1993) carried out a cost-benefit analysis of a work re-entry program for persons with traumatic brain injury. This study found that three quarters of the participants obtained employment, that the ratio of total taxpayer benefits to total program operational costs was 2:1, and the ratio of total taxpayer benefit to the state cost was 4:1. Australian evaluation - (Athanasou, Brown, and Murphy, 1996; Murphy, Brown, Foreman, Young, and Athanasou, 1996; and Murphy and Athanasou, 1994) found comparable findings following spinal cord injuries. Thus there is strong evidence of the potential of back-to-work strategies for people with any type of disability.

While disability management refers specifically to disability in a workplace context, there is evidence that similar return-to-work strategies can be effective in enabling participants on disability benefits programs such as CPP to re-enter the workforce. As discussed in Chapter 5, the GAO (1996i) indicated that the same types of disability management practices used in the private sector could also be used for Social Security beneficiaries. Indeed, the study indicated that the social insurance programs in Germany and Sweden are applying such practices with

considerable success. The Social Security Administration found that successful rehabilitations in its return-to-work initiative save five dollars in benefit payments for every dollar spent.

What is the potential for active return-to-work strategies in enabling social insurance beneficiaries, such as CPP disability claimants, to become re-employed? On the one hand, claimants are by definition "unemployable." But also by definition, CPP claimants have previous work experience. Evidence such as that cited above strongly suggests that a substantial proportion of people *could* be able to be re-employed, given the appropriate types of support and encouragement and workplace accommodations. The evidence also strongly supports early intervention. The longer people are away from work, the less likely they are ever to return to work.

Indeed, one of the conclusions of the evaluation of the National Vocational Rehabilitation Pilot Project (HRDC, 1996a) was that: "There can be good potential for rehabilitation for some CPPD beneficiaries, even after several years on benefits, as the medical condition stabilizes and adjustments to accommodate disabilities have been made." The evaluation found that the pilot project achieved a 43 per cent success rate. This led to a recommendation that CPPD establish a permanent rehabilitation function.

But, as indicated in Chapter 5, it is important to bear in mind the conclusion of the GAO (1996i): even a little bit of success can result in large cost savings. It is *not* necessary to have immediate spectacular successes. Very small, marginal gains in this area can have a very significant long-term impact on the costs of a disability income program. As the GAO says, even "if an additional 1 per cent of the 6.3 million were to leave SSA's disability rolls by returning to work, lifetime cash benefits would be reduced by an estimated $2.9 billion."

Discussion

There is great potential for significant cost savings from disability management and return-to-work strategies. Indeed, return-to-work is probably the area with the greatest possible potential for cost savings, given the previous work experience of participants, along with their employment skills and abilities. Evidence on the return on investment of return-to-work strategies in both the private and public sectors suggests remarkable results.

But there are barriers to effective implementation. Disability management requires initial investment of staff resources and expenditures on case management and rehabilitation. The savings typically accrue to a different cost centre than that which incurs the cost. There can also be resistance from managers, including senior as well as line managers, and human resources departments who are not interested in or do not see the potential of investing in workers who develop a disability.

The evidence indicates that the following strategies are important to the success of return-to-work strategies:

- Intervene as soon as possible: the longer away from work, the less likely a worker will return.

- Provide active case management.

- Recognize that workplace accommodations will frequently be necessary to permit re-entry.

The full costs of long-term disability to an employer and to the taxpayer are not well understood. Tremendous cost savings are possible even with small successes with return-to-work strategies.

C. Job Accommodations

An accommodation is "any modification of the workplace, or in workplace procedures, that makes it possible for a person with special needs to do a job." (Canadian Mental Health Association, 1993). Accommodations include technical aids and devices, as well as physical adaptations to the workplace.

But accommodations also include adaptations to how the work is structured. They can include, for example, modifications to required work tasks and responsibilities or to how they are to be performed, use of flexible hours, provision of break opportunities for workers who tire easily, rearrangement of work materials so that they are more easily accessible (such as placing commonly accessed files within reach of someone who uses a wheelchair), and many other "soft" modifications. The accommodation needs of one senior manager with limited vision included receiving written materials and documents in alternative formats in advance of meetings (Perrin, 1993).

It is noteworthy that workplace accommodations include many adaptations that are frequently available to any worker to address special needs and to enhance productivity. There is no difference in kind between a tool, such as a dictaphone, which enhances the productivity of a senior manager, and a device, such as a computer sound card, which can enhance the productivity of a blind worker.

There is extensive documentation of the potential for accommodations to make employment possible for people with disabilities. For example, part of the scope of an evaluation of the operation of the Job Accommodation Network (JAN) in Canada, sponsored by HRDC (Perrin, 1995) involved consideration of the relative importance of accommodation regarding the employment of people with disabilities. This evaluation concluded that the biggest barriers to the employment of people with disabilities include lack of job opportunities, employer attitudes and limited training and work experience. It nevertheless indicated that accommodation is one important element that can make a difference to the employability of many people and make it possible for them to be productive.

JAN itself has compiled extensive documentation from its own evaluations, research and follow-up with employers, of how a wide range of both "hard" and "soft" accommodations have enabled workers with disabilities to carry out their job responsibilities and to address the needs of their employers. The ILO international report (Samorodov, 1996) indicated that job adaptations can be a very effective and cost-efficient vehicle for the promotion of employment for workers with disabilities - and can sometimes benefit non-disabled workers as well. As discussed earlier, research looking at the return to work of Ontario WCB claimants (Butler, Johnson, and Baldwin, 1995; Johnson and Baldwin, 1993) indicated the importance of job accommodations.

A study by the Roeher Institute (1994b) for the Canadian Labour Force Development Board found that:

> "Over 70% of people with disabilities who require accommodations in mainstream jobs and who believe they have been adequately accommodated are on the job 35 hours or more in a given week. This figure approaches the proportion of non-disabled persons on the job 35 hours or more. Those who do not have adequate accommodations available to them are much more likely to be completely off the job in a given week. Those receiving adequate accommodations are more likely to be moderately and severely disabled than those not receiving or needing accommodations. In fact, individuals receiving adequate job accommodations are generally more severely disabled than the working age population with disabilities as a whole. Yet, they log more hours per week at work than other workers with disabilities."

A prevalent perception is that accommodations are costly. Indeed, the perceived cost of accommodations is a concern of many employers. The evidence, however, indicates that this perception is a myth. In reality, accommodations are typically not expensive. The ILO report (Samorodov, 1996) indicated that:

> "Accommodation costs (job adaptation) for people with disabilities are usually very low, under US$1,000 per person, notwithstanding fears of employers to the contrary. Accommodation costs are not, therefore, a major hindrance to the employment of workers with disabilities and are thus cost-effective."

JAN's data, based on ongoing surveys with employers who have provided accommodations (see Perrin, 1995 for examples of recent data) provide more specific information about the costs of accommodation provided by employers in the United States. Employers who have made accommodations say 18 per cent involved no costs to them, with an additional 50 per cent costing between $1 and $500. Only 5 per cent cost more than $5,000. The mean cost of accommodations was $992 while the median cost was $200.

The same employers also estimated the money their companies saved as a result of being able to hire or retain a qualified employee. Elimination of the cost of training a new employee, savings in workers' compensation or other insurance costs, increase in the workers's productivity, and

other factors. The savings identified averaged 27 times the expenditures they reported in providing accommodations.

Nevertheless, there are exceptional circumstances where an accommodation that is critical to an individual can be costly. Large organizations may be able to absorb these costs, but the JAN evaluation indicated that this would be difficult or impossible for smaller employers. Sometimes funding assistance might be available, such as through provincial vocational rehabilitation services or through HRDC, as well as favourable taxation. But few employers are aware of these, and the delays and bureaucratic procedures involved in getting government support are frequently incompatible with running an efficient business operation.

HRDC formerly had a separate fund which could be used for accommodation expenses. An evaluation of the effectiveness of Canada Employment Centres (CECs) for people with disabilities (Perrin, 1994) indicated that this fund was little known among CEC staff, bureaucratically complex and time consuming to access. As a result, it was rarely used. It was also designated for workplace training. Now Human Resource Centres Canada (HRCCs, the new term for CECs) managers have discretion to pay for selective accommodations. But these expenditures must come out of general HRCC budgets, providing little incentive to do so.

As the next chapter indicates (and see Baker, 1992), grant-levy schemes such as those used in Germany and France, in addition to providing incentives for employers to hire people with disabilities, including people with severe disabilities, also produces a fund which can be used to fund exceptional accommodations.

Accommodation costs are most likely to be high when they involve personal care or support. These may include, for example, attendant care or job coach support to a person with a developmental handicap. Because of their qualitatively different nature, high levels of personal support, such as for individuals with severe disabilities, are usually treated differently than other forms of accommodation. It is probably unrealistic to expect employers to cover these costs. But there may be other ways in which such services could be provided. For example, the study of transitional employment services for individuals with severe mental disabilities discussed earlier (Conley, Azzam and Mitchell, 1995) indicated the need for support from agencies to permit employment of severely handicapped people needing high levels of assistance. As discussed in Chapter 6, the availability of personal support, especially when directed by the individual, can assist in employability.

The JAN evaluation (Perrin, 1995) identified employer attitudes and lack of information or misinformation as the biggest barrier to providing accommodations in the workforce. There is a general lack of awareness of the potential of accommodations to enable many people with functional limitations to work. There is also a need for practical "how-to" information on how to make accommodations in specific situations.

A study exploring career development among managers and other employees with disabilities within the Ontario public service (Perrin, 1995) identified employer and supervisor attitudes as critical. This study identified factors associated with career success. It found that with the right

attitude, arranging for the actual accommodation usually turns out not to be a big deal, even for employees with severe disabilities. This evaluation found that the same basic factors that apply to the management and development of *all* employees also apply to the management and development of employees with disabilities. In particular, the role of the direct manager, and an openness to taking an individual approach and to good communications with the employee, were critical to the career success — and performance — of employees with disabilities.

HRDC's evaluation of JAN's operation in Canada[1] (Perrin, 1995) concluded that it offers a useful service to employers and others; but that its potential effectiveness and reach is limited by organizational factors. The evaluation recommended that JAN's services in Canada be refocused so that it could play a stronger role as an information resource to increase awareness of and interest in accommodation.

As discussed in the next chapter, the United States government, in support of implemeniation of the Americans with Disabilities Act (ADA), funds a variety of technical resource centres and other services to provide information and support to employers, rehabilitation workers and individuals about how to make accommodations.

It is worth noting that the principle of reasonable accommodation, which puts the onus on employers and others, is enshrined in employment equity and human rights legislation in Canada, as well as in the Charter of Rights of Freedoms, as the Supreme Court recently affirmed. It also is reflected in the legislation and policies of a number of other countries.

Discussion

Lack of accommodations represents one of the major barriers to employment of people with disabilities. A common misunderstanding is that job accommodations are usually expensive. The reality, however, is that the vast majority of accommodations are of low cost, and many, such as modifications to work tasks or work site arrangements, require no expenditure at all.

The major barriers with respect to accommodations are attitudes and lack of information, both about the potential of accommodations to permit people with disability to be able to do productive work, and about the practical "how-tos" of implementing accommodations in specific situations. Addressing these barriers could result in increased employment opportunities for people with disabilities.

Employers could be primarily responsible for providing accommodations, other than for exceptional circumstances. Government could be mainly limited to making information and support available to counter the myths and lack of awareness concerning job

accommodations, as the United States government is doing in support of ADA. As noted earlier, the evaluation of JAN identified the potential of JAN to play a broader role in increasing awareness and interest in accommodation and in supporting government initiatives such as Employment Equity legislation. There may also be other ways of addressing these needs.

D. Wage Subsidies and Employer Incentives

"Wage subsidies are put in place by governments as an incentive to the private sector to increase the training and employment opportunities for persons with disabilities." (Raskin, 1995) They are intended to compensate employers for lost productivity. They act in two ways: "First, they reduce effective wage costs to employers; second, they enhance the employability of people with disabilities who are seeking work (Samorodov, 1996)." Most wage subsidies are for limited duration, ranging from months to years, and sometimes a sliding scale of reduced subsidies is used.

The evidence indicates that the effectiveness of wage subsidies is mixed. Indeed, the ILO international report noted that, given the fact that wage subsidies are found in many countries, the lack of evaluative efforts is striking (Samorodov, 1996). The two ILO reports (Raskin and Samorodov cited above) provide useful summaries of the state of the art.
As these ILO reports discuss, wage subsidies are intended to help with entry into the labour market, especially for people with little or no work experience. They can provide work experience for individuals who may have trouble obtaining it without some form of assistance.

On the other hand, subsidies can have a number of disadvantages. For example, being categorized as eligible for a wage subsidy can negatively reflect on the capabilities of individuals so categorized and lessen their chances of employment. Individuals who are not retained following a subsidized placement, in particular, may have difficulty obtaining future employment. Thus, it is uncertain that the use of wage subsidies will result in long-term employment following the end of the subsidy. Some employers may use subsidies to "churn" workers through their firm and as a substitute for paying the expenses themselves of training new employees. Subsidies could end up providing employers with a cheap pool of labour, taking advantage of rather than benefiting the subsidized workers. (Samorodov, 1996).

Samorodov (1996) cites an Australian study indicating that employers prefer subsidies to quota or other systems which provide a compulsion to hire. Yet the same study identified only a limited effect of the subsidies.

The experience in Quebec is indicative. Quebec has the most experience in providing employer subsidies for hiring individuals with disabilities through its *Contrat d'intégration au travail* program. A recent evaluation of this program (SOM, 1996) indicated that the positive effects were temporary. It did not appear to increase the income, employment or quality of life of program participants. This evaluation, as well as an earlier review by Le Vérificateur Général du Québec (1993), indicated that the program did not provide for specific individual objectives regarding improvements in productivity and behaviour or what would be required to maintain the person on the job. The Office des Personnes Handicapées du Québec, the sponsor of the

program, did not maintain sufficient records to effectively monitor the program, the nature of the clientele and the activities of employers. As a result, some employers hire persons who are not eligible for subsidies or receive higher subsidies than required.

Subsidies can also result in dead weight (jobs that would not have been created otherwise) and displacement (employment of a subsidized individual at the expense of someone else). A European Commission report (European Commission, 1996a), considering the impact of subsidies across all target groups, says that only 10 to 24 per cent of the expenditures result in net job gains.

On the other hand, despite these dangers, there can be some potential benefits of employer subsidies. The same European Commission report also notes: "Even if the [wage subsidy] scheme is associated with strong displacement effects, it might, nevertheless, be justified on equity grounds as a means of sharing out available work more justly."

The two ILO reports indicate that: "Wage subsidy measures that emphasize the individualized needs of the participant may be the most successful (Raskin, 1995; Samorodov, 1996)." These reports single out the Individualized Subsidized Job (ISJ) component of the Job Development Program (JDP), part of the Canada Jobs Strategy, formerly offered by the Employment and Immigration Canada (now HRDC) as an exemplary model (Raskin, 1995).

An evaluation of the Job Development Program identified the ISJ component as the most cost-effective approach of the various JDP components. It resulted in improved employability and earnings for participants with disabilities. Raskin (1995) observed that the "ISJ was not only cost effective for the quantitative element (cost benefit) but was also qualitatively beneficial," as it consisted of training options tailor-made to the needs of individuals and was closely linked to the private sector. Raskin noted that a major reason for the success of this program was the individualized nature of the placements for disabled participants, which included accommodation of the work site and attention to the individualized needs of the participant. He also indicated that those ancillary activities such as pre-training outreach *that directly target groups of persons with disabilities* to ensure participation levels that are representational was another reason for the success of the program.

Similar results were found in an evaluation of the Program for the Employment Disadvantaged (PED), formerly provided by EIC (Social Policy Research Associates, 1984). The purpose of this program was to aid in the employment of employment-disadvantaged people, including people with disabilities. It combined subsidies to employers, along with assistance for workplace modifications where needed, coordination, counselling and other forms of support by both Canada Employment Centre staff and through community-based agencies.

This evaluation found that the program was highly effective. For example, some 16 per cent of the participants with disabilities were still employed with the PED employer following the completion of the program and at the time of the follow-up evaluation survey; another 24 per cent went on to employment with other employers. In addition, the evaluation indicated that the

program led to improvement in productivity, job skills, employability, job satisfaction and related matters.

There can be other forms of incentives to employers besides subsidies. These can range from tax exemptions for work site modifications and accommodations to the provision of support from community-based agencies. A transitional employment program (Conley, Azzam and Mitchell, 1995) which provided intensive support to individuals with severe disabilities and to employers was discussed above. The supported employment model discussed later in this chapter is another example of an approach which uses an external agency to provide the support necessary to ensure that the employees are productive.

A model is Projects with Industry (Policy Studies Associates, 1986), operational in the United States for some time. This program involves a partnership between business, industry, labour and the rehabilitation community, ultimately leading to competitive employment for individuals with disabilities. The program combines training at realistic work settings, coupled with supportive services. Past evaluations of the program indicated its effectiveness in leading to subsequent employment for a significant proportion of the participants.

Also, as discussed in the next chapter, the grant levy or redistributive model provides incentives for employers to hire individuals with disabilities. The European Commission (1996a) report on employment in Europe indicated that subsidies are one way of reducing social costs to employers, but: "In most Member States . . . policy to reduce labour costs for particular workers has predominantly taken the form of reducing social contributions on employers rather than the payment of subsidies as such." Raskin (1995), in his ILO review, concludes that barrier removal is more effective than subsidies.

Discussion

The effectiveness of wage subsidies to employers is mixed. Generally, only a minor proportion of the expenditures result in employment that endures in some form beyond the subsidy period. Other approaches, such as barrier removal, generally appear to be more successful. Subsidies appear to be most effective when they are part of a coordinated approach involving other forms of support to the individual and to the employer, when they are specifically tailored to address the identified needs of the individual, and when follow up and monitoring is provided.

E. Supported Employment and Sheltered Work

i. Supported Employment

Supported employment involves training and work at regular work settings. The unique feature of supported employment is the provision of a job coach who provides support and training to the individual, and who is responsible for helping to get the job done. As O'Brien (undated) says, supported employment:

> "Expands the focus from the person alone to the person plus a skilled coach. Instead of simply assessing the job ability of the person alone, as practitioners within a typical continuum of day services do, supported employment practitioners consider what the person can do with the assistance of a job coach. This shift in focus allows many previously excluded people to work."

A key component to the success of supported employment is the flexibility to provide as much or as little support as the client needs, on an ongoing basis. Initially, support is often intensive, often on a one-on-one basis. This emphasis enables clients to be placed who do not initially possess all the necessary work or social skills required for immediate job success. As the worker demonstrates independence, the amount of support is gradually reduced (Perrin, 1986).

Supported employment involves a place-train model. This is the reverse of the traditional rehabilitation train-place approach. Indeed, with the traditional model of rehabilitation, as discussed later, the "placement" often never happens. Another critical difference from traditional rehabilitation is the role of the job coach. As indicated above, the task of the job coach is not just to help train the worker, but to work together with the participant as needed to get the job done and to satisfy the requirements of the employer.

Supported employment is a relatively recent innovation. It was first developed in the early 1980s by Paul Wehman and his associates at the Rehabilitation Research and Training Center at Virginia Commonwealth University (Wehman and Hill, 1986; Wehman and Kregel, 1984; Kregel and Wehman, 1996). In the mid 1980s, there were only a handful of largely experimental programs in Canada (Perrin, 1986, 1987). But over the last ten years, supported employment has mushroomed, particularly in North America. It is also attracting worldwide attention, with programs in many other countries as well (Lunt and Thornton, 1993).

Supported employment is now a field of study in its own right. There is a developing body of literature, both practically oriented and scientific in nature.

Supported employment has been used most extensively with individuals with intellectual disabilities. It has also been used, to some extent, for people with psychiatric disabilities. But the ILO report (Samorodov, 1996) indicated the potential for application of the model to other client groups, citing examples. It suggested the approach is especially good for younger workers.

Supported employment has been used primarily with people who are not considered able to work competitively, and who otherwise would probably be placed in a sheltered workshop. With many individuals, the support can be completely or largely withdrawn, so that they can eventually work independently. Others, however, require intensive ongoing support in some form.

There are many examples of individuals earning minimum or competitive wages. But probably in many situations, wages are at sub-minimal rates or none. Income from support usually serves as

a supplement to income security rather than as a replacement. For example, a survey of Canadian agencies providing supported employment services in 1988 (cited by Raskin, 1995) found that 21 per cent of participants no longer needed social assistance, and an additional 24 per cent were less dependent. But 55 per cent of participants were still dependent on social assistance to the same level as previously and almost 50 per cent of supported workers earned less than $50 per week.

Despite impressive gains, most clients probably are still not working at full productivity. A majority of placements involve part-time work. Supported employment approaches have enabled people with even very severe disabilities to work productively in regular work settings. Indeed, the model was originally developed as a means to enable individuals with very severe disabilities to work in integrated settings. Nevertheless, concern has been voiced as to the extent to which supported employment programs are indeed serving the most severely disabled. Rankin (1995) cites findings from the 1988 survey of Canadian supported employment programs which indicate that a majority of clients are mildly to moderately disabled. He indicates that federal funding policies which limit the length of time for which a person can receive program support may serve as a disincentive to serving individuals with severe disabilities who may require ongoing support.

Supported employment placements offer varying degrees of integration (Kregel and Wehman, 1996; Rankin, 1985). Individuals often work side by side with regular workers. In other cases, they may work within an enclave or in other settings which provide limited contact with other workers. As Rankin indicates, the degree of integration provided by supported employment is a concern. Nevertheless, supported employment offers more potential for integration than other options for this client group.

A recent innovation or variant is to make use of natural supports, such as co-workers or neighbours, as an alternative or supplement to the job coach (O'Brien, undated; Conley, Azzam and Mitchell, 1995). This approach can provide for truer integration, with assistance and greater contact from "real" people rather than from paid staff. Kregel and Wehman (1996) report on a survey which indicates that a majority of supported employment provider agencies in the United States are using natural supports.

In theory, there is potential for greater cost effectiveness and for supporting a greater number of persons when making use of natural supports. With limited evaluation to go by, it is as yet unclear if this is indeed the case. The 1996 Kregel and Wehman study suggests that staff time on job sites has changed among about one third of agencies using natural supports. The role of paid staff shifts from providing support directly to an individual, to arranging and supporting others to do so. This can require significant coordination, along with initial efforts in arranging for the provision of assistance. Follow-up and ongoing support may also be required, with the paid staff person stepping in when problems may develop.

ii. Impact of Supported Employment

There have been a number of research studies examining the impact and the benefits and costs of supported employment. For example, Conley, Rusch, McCaughrin, and Tines (1989) review the findings from a number of cost-benefit analyses as well an longitudinal studies which indicate that:

> "Although costs of supported employment are greater than benefits during the first years of implementation, costs decrease and benefits increase over time because employees increase both their hours and average hourly wages, while the amount of support needed on the job decreases."

A review of the literature, with a good bibliography of studies looking at the impact of supported employment came to a similar conclusion:

> "The research demonstrates that supported work programs are furnishing positive employment outcomes for persons with mental handicaps. These programs have provided a financial benefit to the supported workers through increased earnings and a benefit to taxpayers in decreased program costs. Although costs to taxpayers in the first years of program implementation may exceed financial benefits, the research suggests a substantial increase in benefits is found in subsequent years (Jamieson and Hawkins, 1992)."

Johnson, Lewis and Bruininks (1993) discuss the status of evaluation of supported employment. They describe a case study which provides a model of a benefit-cost analysis that found a benefit-cost ratio of 2.55 across 13 different program sites. But they caution that there is lack of consensus on the goals and outcomes that should be used in evaluation of supported employment. They state that: "Increasingly, researchers . . . have even argued that valuing supported employment strictly on the basis of cost-effectiveness is illegitimate, and that supported employment should be valued primarily from its capacity to assist individuals in achieving social and community integration."

Agencies appear to have had the most success in finding placements for supported employment in small business settings (Perrin, 1987; Rankin, 1995), but there are many notable exceptions. There have been difficulties in arranging for placements in the public sectors, due to a number of systemic barriers related to formal hiring policies (Drug, 1993).

Individuals with disabilities who have the opportunity to participate in supported employment are very positive, and prefer it to other alternatives (Kregel and Wehman, 1996). People want to work, for social as much as for economic reasons. They like the opportunity to be in a regular setting and to interact with other people who do not have a disability. They like having their work valued through pay, and they like getting a regular pay cheque.

Supported employment can be structured so that employers can hire people with even severe disabilities and expect the work to get done. Agencies have had most success marketing supported employment to employers based on a business case, rather than on "good cause" marketing.

The National Institute on Disability and Rehabilitation Research (1994) concluded that: "Supported employment has created unprecedented employment opportunities for people previously perceived as too severely disabled to engage in meaningful work." ILO, in its reviews of the cost effectiveness of the full range of employment services, found supported employment as the most promising model. For example, Raskin (1995) stated: .

> "Concerning the effectiveness of various types of wage subsidy and supported employment programs, evaluations indicate those that emphasize the individualized placements in the private sector that are designed to meet the personal requirements of each trainee, and which provide participants with an opportunity to interact with non-disabled co-workers and to form relationships offer the best prospects for success."

ILO's international review of the cost-effectiveness of policy options for workers with disabilities (Samorodov, 1996) concluded that:

> "Supported employment — trying systematically to integrate workers with disabilities into open employment alongside able-bodied workers — can best be recommended as really efficient in terms of costs and benefits. Over time it may be expected to result in significant returns on investment. . . . Research shows that these programmes, even in the initial high-cost phase, are markedly cheaper than traditional day centres, and especially than sheltered employment schemes. . . Supported employment is thus a cost-effective alternative to other more traditional approaches; it also reduces people's usage of and dependency upon day services."

iii. Sheltered Work

The traditional approach to "training" people with disabilities who could not find fully competitive employment has been to place them in sheltered workshops. Workshops offer simulated work, generally with the stated objective of training people in work skills. In practice, few people move on, and the "skills" and behaviours they develop are the contrary of what is appropriate for regular work. Token "wages" only are offered.

Recognition of the limitations of sheltered workshops is increasing, as is awareness of the superiority of alternatives such as supported employment. For example, Conley et al. (1989) points out that supported employment programs have resulted in the long-term maintenance of approximately 50 per cent of their workers for at least one year alongside non-handicapped workers. By contrast, traditional sheltered workshops have reported that only about 10 per cent of their workers were placed in integrated work settings over the same time period.

As a result, workshops are being phased out in favour of supported work and other alternatives across Canada, the United States and Australia (Lunt and Thornton, 1993).

Sheltered work is still widely used in Europe. But this is largely based on a different model from that used in North America, closer to what has been termed "protected work". Sheltered work in Europe tends to be based on an economic rather than the social work orientation in North America, with more emphasis on productivity. These centres often have able-bodied workers as well as workers with disabilities and tend to provide real pay.

Quebec, unlike other jurisdictions in Canada, has funded Centres de travail adapté (CTAs), which operate more like the European model of sheltered work. For example, CTAs are expected to operate as non-profits enterprises. The proportion of able-bodied workers may vary from 0 to 49 per cent.

But there are still severe limitations to this model. For example, two recent evaluations of Quebec's CTAs (Le Verificateur General du Québec, 1993; SOM, 1996), found that the economic interests of the CTA worked at cross purposes to their stated objectives of assisting workers with disabilities to enter the regular workforce. Because of a desire to improve their productivity, they frequently hired workers who did not meet the criteria for the program, and were reluctant to let their most productive workers go for regular employment. Similar findings were found in the CTAs in France (Velche, 1995).

iv. Discussion

The supported employment model has proved itself a better and more cost-effective alternative than sheltered work in almost all respects. It supports integration and is very popular with individuals, who welcome the opportunity to do real work in real settings. It provides opportunities for people previously perceived as too severely disabled to engage in meaningful work to work in regular employment settings. There is ample evidence of the cost effectiveness of supported employment, although costs can be high in the initial stages. The ILO has identified the superiority of the supported employment model to other alternatives in terms of benefits to individuals as well as cost savings, and has indicated the potential for widespread use of the approach.

F. Vocational Rehabilitation

A great deal falls under the rubric of "vocational rehabilitation". In Canada, vocational rehabilitation is provided according to source of disability, disability type, source of income, or attachment to the work force. The Workers' Compensation Boards (WCBs) provide vocational rehabilitation to those injured in the workplace; the Canada Pension Plan (CPP) has a pilot vocational rehabilitation project for recipients of CPP disability benefits; private

employer insurance companies provide or purchase vocational rehabilitation from private sources.

In essence, the various types of employment interventions discussed in this chapter can be considered as forms of vocational rehabilitation. Samorodov (1996) defines rehabilitation programs as those which "treat and retain workers with disabilities and return them to gainful activity." Traditional approaches to rehabilitation view training/rehabilitation as a discrete step separate from employment, using a "train then place" model. As discussed elsewhere in this chapter, this approach is changing, with supported employment using a "place and train on the job" model. There is increasing recognition that rehabilitation is most likely to be effective when it is as closely related as possible to employment.

Individual vocational rehabilitation programs generally are those which tailor the services provided or the goods and services purchased to fit individual needs. Vocational assessments, vocational planning, training, retraining or education, job placement and follow up constitute the core of individual vocational rehabilitation programs. Related to these services is the provision of living allowances and disability-related supports and services such as home or vehicle modifications, orthotics and prosthetics, wheelchairs, private tutoring, treatment programs, and mobility training. Goods and services are purchased from a wide range of suppliers, both public and private. Some vocational rehabilitation programs, WCBs for example, provide subsidies and other strategies to encourage employers to hire injured workers.

Vocational rehabilitation is sometimes thought of in terms of those services funded through the federal/provincial VRDP agreement. Each provincial and territorial government delivers an individual vocational rehabilitation program, cost shared with the federal government under the *Vocational Rehabilitation of Disabled Persons* (VRDP) *Act* and Agreement - except for Quebec, which now has a separate provincial delivery system for vocational counselling services.

In addition, there is a large network of volunteer community-based agencies which provide individual vocational rehabilitation services. These agencies can be provincially funded and cost shared under the VRDP agreement, or they can be funded as employment assistance services by HRDC, as well as through other sources. Some agencies providing vocational rehabilitation are disability specific, such as the Canadian Paraplegic Association, the Canadian National Institute for the Blind, and the Canadian Hearing Society. Others are more generic, such as the Neil Squire Foundation, the Canadian Association of Independent Living Centres, and Goodwill Industries. A key network is Associations for Community Living which delivers individual vocational rehabilitation services through such measures as supported employment programs and vocational assessment and training programs in sheltered workshops.

The *VRDP Act* is an enabling financial transfer mechanism which allows the federal government to enter into agreements with the provinces and territories to contribute to certain provincial and territorial costs of vocational rehabilitation programs. Currently there is a

standard agreement with all provinces and territories. A variety of programs are cost shared under the VRDP Agreement. These include individual vocational rehabilitation programs, vocationally related portions of alcohol and drug programs and mental health programs in the community and in psychiatric hospitals; an array of agency delivered programs; supported employment programs; and sheltered workshops. There *is* some similarity of programming across provinces is the individual vocational rehabilitation programs, which are in turn similar to the vocational rehabilitation programs of WCBs and CPP.

Support for post secondary education is a major feature of the individual vocational rehabilitation programs of the provinces. VRDP cost sharing is available for tuition, books and supplies, living allowances and support services such as attendants, interpreters, tutors and technical aids, provided to individuals. Some provinces coordinate or harmonize the assistance with the federal and provincial student loans program. Several provincial governments provide funding for special needs counsellors in community colleges and in some universities, often cost shared under VRDP.

i. What works

There have been no evaluations of the effectiveness of the VRDP Agreement. This would be challenging to do, given that VRDP is a mechanism to transfer funds to provincial and territorial treasuries according to rather general provisions and guidelines. It is up to each province and territory to establish eligibility and to determine the activities relating to the vocational rehabilitation of disabled persons. The effectiveness of the VRDP Agreement as a transfer mechanism would have to be evaluated, for example, in terms of federal objectives in transferring the dollars, and in terms of provincial objectives for obtaining the dollars. Basically there are 12 different provinces and territories that deliver programs through various departments and ministries. There are also many different criteria for eligibility, depending on the types of programming - mental health, alcohol and drug, as well as individual vocational rehabilitation, for example.

The requirements for provincial reporting of activities under VRDP are basically limited to the numbers of clients served. There is no requirement for provinces to report on those who have obtained employment or on other impact measures.

One provincial program where outcome statistics are available is the Vocational Rehabilitation Services (VRS) program delivered by the Ontario Ministry of Community and Social Services. Based on 1992-93 statistics for this program, Raskin (1995) found that: "The outlay for vocational rehabilitation services is clearly cost beneficial when compared to the wages the client earns, and is cost beneficial in all cases when compared to the option of maintaining persons with disabilities on social assistance." In 1992-93, $20.7 million was expended on the VRS program in direct client-related expenditures, with an additional amount for staff and administration. Of those clients who received vocational training or restorative services, 56 per cent were employed when their cases were closed. On average, about 5,000 new cases are opened each year.

In the disability management section of this chapter, we refer to research that examined the impact of vocational rehabilitation on the probability of post-injury return to work among claimants of the Workers' Compensation Board (WCB) of Ontario (Allingham and Hyatt, 1993; Raskin, 1995). This research showed that vocational rehabilitation is having its intended effect — it is reducing the negative impact of residual disabilities on the return to work of injured workers, thereby reducing benefits and social costs. In 1992, the Board paid $1,797 million in long-term disability benefits, and $561 million for rehabilitation. A total of 28,704 persons or 7.6 per cent of claimants were referred for vocational rehabilitation and 46 per cent of these were rehabilitated, most returning to work with the enterprise that employed them at the time of the accident.

It is not always possible to compare vocational rehabilitation programs to each other. The needed data are not usually in place, and definitions of eligibility as well as program and service objectives differ. For example, in the United States, an attempt was made to compare the Veterans Affairs VR program with the State VR programs. In the Veterans' program, 8 per cent of eligible veterans were placed from 1991-1995. In the State program, 37 per cent were placed in suitable jobs. However, the Veterans' program tended to concentrate on higher education and defined a suitable job as a position consistent with the veteran's aptitudes, abilities, and interests. In contrast, the State VR program provided a wide range of services and defined a suitable job as including non-wage earning jobs. Most clients in the state program had severe disabilities. Veterans Affairs spent $20,000 on each employed veteran and $10,000 on each program dropout, with more than one-half of costs going towards veterans' subsistence allowances, while State VR programs spent on average about $3,000 on each rehabilitated client and about $2,000 on each dropout, none of which covered clients' living expenses (GAO, 1996j).

An American-based review of the literature (Weed and Lewis, 1994) surveying the past 25 years overwhelmingly identifies the benefits of rehabilitation for people with disabilities regardless of referral or payment source. These studies showed that the provision of rehabilitation services can be a cost-effective approach to assisting people with disabilities to work, and that earlier referral reduces the cost of rehabilitation and increases the likelihood of employment. As indicated earlier, the evaluation of the National Vocational Rehabilitation Pilot Project Evaluation for CPP (HRDC, 1996) identified the potential for rehabilitation even among many long-term beneficiaries, and recommended that CPP establish a permanent rehabilitation function.

In its research on transitional programming, The Roeher Institute (1994b) identified a number of factors contributing to the success of people with disabilities making transitions from school to work. These included access to needed disability-related aids and devices, adequate accommodations in the workplace, access to on-the-job training, participation in other forms of training, access to the personal support required to manage daily living activities, and access to rehabilitation services. This study also identified the importance of the following factors:

- Building on the individual choices of people and in so doing, promoting individual motivation and skill development;

- Involving family members and friends in the transition process;
- Early planning in the high school careers of students;
- Work experience through cooperative education and other arrangements;
- Keeping employers informed about the available pool of potential workers with disabilities.

Indeed, as noted earlier, one of the conclusions of the National Vocational Rehabilitation Pilot Project (HRDC, 1996) was that: "There can be good potential for rehabilitation for some CPPD beneficiaries, even after several years on benefits, as the medical condition stabilizes and adjustments to accommodate disabilities have been made." The evaluation found that the pilot project achieved a 43 per cent success rate (based on individuals' voluntary participation of the project). This led to a recommendation that CPPD establish a permanent rehabilitation function.

The ILO review (Samorodov, 1995) of the cost effectiveness of policy options for workers concluded that each dollar spent on vocational rehabilitation sets or maintains in motion a stream of output of several dollars. "In sum, funds that are expended on vocational rehabilitation programmes are repaid, on average, many times over. Rehabilitation can thus be considered a really cost-effective way of promoting the return to work and employment of people with disabilities."

ii. Problems and Limitations

Rehabilitation is not always effective. A GAO (1993) evaluation (*Vocational Rehabilitation: Evidence for Federal Program's Effectiveness is Mixed)* noted wide disparities in the types and amounts of services provided, with insufficient data to relate these to outcomes. That review indicated that short-term gains of rehabilitation often do not appear to endure. These findings led to a recommendation for a longitudinal study to explore broader issues such as who can be served, at what intensity, and with what results.

The study noted that just 5 to 7 per cent of those potentially eligible actually were served by state/federal vocational rehabilitation programs. The GAO recommended a longitudinal study to explore broader issues such as who can be served, at what intensity, and with what results. In a more recent study, GAO (1996g) stated that vocational rehabilitation has played a limited role because of restrictive state policies. 'Beneficiaries are generally uninformed about the availability of VR services and are given little encouragement to seek them."

Individuals with disabilities and referring agencies have complained about difficulties in obtaining access to vocational rehabilitation services and programs. Waiting lists for some provincial vocational rehabilitation programs can be as long as a year or more. On the other hand, some Workers' Compensation Boards have made changes that include early intervention and a right to early vocational assessment and counselling (Roeher Institute, 1992).

Thus a major problem with vocational rehabilitation services is who actually receives services. Only a small proportion of those in need and who could benefit from these services actually obtain them. Due to lack of data, it is not always clear how priorities are set, and which types of clients are most likely to receive services. It is not clear whether those with severe disabilities and most in need are most likely to receive services. This is true in Canada as well as in the United States.

The provincial vocational rehabilitation programs exclude from eligibility those who are eligible for vocational rehabilitation from Workers' Compensation Boards and through the department of Veterans' affairs. Those in receipt of CPP are not formally excluded and can be referred to provincial programs for vocational rehabilitation. While this has not been expressed as a problem, experience in the United States may be instructive.

The Social Security Act states that as many individuals applying for disability benefits as possible should be rehabilitated into productive activity. To this end, people applying for disability benefits are to be promptly referred to state vocational rehabilitation (VR) agencies for services intended to prepare them for work opportunities. The federal government reimburses the state for successful outcomes. However, it was found that the success-based reimbursement system was ineffective in motivating VR agencies to accept beneficiaries as clients. Delayed VR intervention can cause a decline in receptiveness to participate in rehabilitation and job placement activities, as well as a decline in skills and abilities (GAO, 1996g).

The Roeher Institute's (1992) report on Canada's employment-related programs for persons with disabilities describes a range of problems regarding the way in which vocational rehabilitation programs in general are delivered and how they are organized, which make it difficult for individuals to link into training, education, and employment systems:

- Eligibility criteria make it difficult for people with disabilities to qualify for training, education and job placement opportunities;
- Wishes, interests or needs of the client may not be given adequate consideration;
- Vocational counsellors may have difficulties providing applicants with an overview of the full range of vocational options;

- There is a disturbing increase in assessment procedures without a corresponding investment in vocational counselling services, leading to delays in accessing training or other services;
- There is a shortage of counselling and planning support which is a key barrier to employment and training opportunities.

As the next chapter indicates, models of support which emphasize individual control and responsibility are usually more effective than models where professionals decide unilaterally what is best for someone else.

A study of financial assistance available to post secondary students with disabilities (National Education Association of Disabled Students, 1993) concluded that 44 per cent of the disabled post secondary students indicated that their income from all sources was not sufficient to cover their education-related services and equipment costs, considering their disability. This study also indicated that the provincial VRDP programs need to allow students more freedom to choose their program of study, and greater opportunities to pursue education beyond the undergraduate level.

Client involvement in the development of policy and evaluation strategies can also be a significant factor. For example, a participatory action research approach, involving both clients and professionals, was used to explore key issues and to prioritize goals for the Reauthorization of the Rehabilitation Act in the United States. Both groups identified employment as the most serious problem facing persons with disabilities. But clients and professionals had differing views regarding goals and priorities for rehabilitation policy (Cantrell and Walker, 1993). An evaluation of the consumer involvement process in the Mainstream 1992 Review (Perrin, 1993) identified how consumer involvement led to greater trust on all sides and to a better product. With upcoming federal/provincial/territorial discussions on the future of VRDP, it may be worth considering how clients should be involved in the process.

iii. Discussion

Vocational rehabilitation *can* work in getting individuals into employment and back into jobs. It has a significant cost benefit to the taxpayer, and reduces costs to income support programs and to insurers. It plays an important role for individuals with disabilities who benefit both economically and in terms of quality of life.

The biggest limitation to the effectiveness of rehabilitation is lack of access. Only a small proportion of those people who could benefit from these services are able to access them.

Not all approaches are equally effective. There is a lack of evaluation or even the maintenance of basic data needed to determine who is being served and to what effect. In general, vocational rehabilitation is most effective when it is individualized and closely oriented to the labour market. Innovative approaches to rehabilitation recognize that rehabilitation/training and

employment should not be viewed as discrete steps. Without attention to the support needs after a person starts or returns to work, gains may be short-term only.

G. Impediments to Greater Employment of People with Disabilities

As this chapter shows, there is overwhelming evidence of the *potential* of many more people with disabilities to work in regular settings. There is strong evidence of the *potential* of a variety of strategies such as disability management, vocational rehabilitation, supported employment, and workplace accommodations.

Why is it, then, that there has been no significant breakthrough in the employment of people with disabilities? The following discussion examines the systemic impediments to employment of persons with disability - discounting labour market effects, such as the fact that high unemployment rates have a "discouraged worker" effect on persons with disability, and that individuals may fear of losing eligibility for income benefits if they attempt to return to the workforce.

i. Barriers to Employment

The greatest impediments to the employment of people with disabilities are non-employment barriers. This has been a theme of Canadian parliamentary Standing Committee reports going back to the original *Obstacles* report in 1981. It has been a theme in representations of clients and consumer organizations over the years, as reflected, for example, in the report of the Mainstream 1992 review. As cited earlier, the Roeher Institute's (1992) report on Canada's employment programs for persons with disabilities showed that lack of supports was a bigger barrier to employment than severity of disability.

A European report (European Day of Disabled Persons, 1996) stated that:

> "It is essential to place disabled people's restricted access to employment within the wider framework of discrimination and to recognise the barriers that constrain disabled people *outside* the workplace. Indeed, increased employment opportunities will only be effective alongside reforms in other policy areas."

A *combination* of factors are necessary for a person with a disability (or for anyone else, for that matter) to be able to work. As the European Commission (1996b) put it:

> "If a disabled person has a good personal assistance programme, has received a good education and has excellent employment opportunities, the investment made in personal assistance, education and employment may be wasted if there is no transport infrastructure to enable them to travel to and from work."

Following are some of the major barriers preventing many people with disabilities from working:

Accessible and Affordable Transportation. A job opportunity is of no use unless a person with a disability has some means of getting to it. Few people with disabilities are able to afford an automobile, and for many, public transportation is not accessible. Alternatives, such as taxis, can be non-existent or unaffordable. There are alternative transportation systems for people with disabilities in many (but by no means all) communities. It is beyond the scope of this paper to discuss the limitations of these systems, but it should be noted that they are now being reduced in many communities because of budgetary considerations.

Education, Training and Work Experience. Education and experience is becoming increasingly important for everyone in today's labour market. It was shown earlier in this study that educational levels of people with disabilities are lower than for others. The difficulties people with disabilities have had obtaining access to employment services at Canada Employment Centres (now HRCCs), including access to training programs were discussed above.

Education is not a federal responsibility. The federal government is devolving direct support of training to the provinces. Nevertheless, the federal government could still use other existing mechanisms, such as dedicating some support for post secondary education specifically to students with disabilities, through its support for literacy, and through its youth initiative. The Federal Task Force (1996) recommended that agreements with the provinces for the devolution of employment services should build in provisions to provide for equitable services for people with disabilities.

Despite the mixed effectiveness of employer subsidies, this chapter showed that a variety of programs designed to assist people with disabilities obtain workforce experience, including some previous EIC programs such as the ISJ, were effective. Providing training and experience on the job is also a basic premise of supported employment.

Social isolation and segregation. As shown in Chapter 6, it is difficult for individuals to learn the basic social skills necessary for interacting with others - including skills and habits necessary for interacting in the workplace and self confidence - when they are isolated.

Personal supports. The critical importance of supports to the employment of people who require this form of assistance has already been discussed. Eligibility requirements for personal assistance and other forms of supports frequently act as a barrier to employment. For example, in some situations, eligibility for supports is tied to specific programs or settings, such as sheltered workshops. These supports would be lost if a person leaves the segregated setting for employment. In other situations, a person needs to be declared "unemployable" to qualify. Eligibility for provincial vocational rehabilitation services requires a person to demonstrate the potential to be "competitive" and "independent." Depending upon how this is interpreted, it could rule out eligibility for people who can work, but only with supports, creating a catch-22 and discriminating against the people who may need the supports the most (Rocher Institute, 1992).

Supports, including aids and devices, are discussed in Chapter 6.

Accessibility. Accessibility is more than a ramp to the front door. It involves other factors, such as the job design, how an individual is treated by supervisors and coworkers, openness to reasonable accommodations, and so forth.

Extraordinary Costs of disability. People with disabilities bear many additional costs arising specifically from their disability (Perrin, 1991; Task Force, 1996). In many cases, these can be quite substantial. They may face considerable extra costs in accepting employment (such as extra transportation or personal assistance expenses) which could make employment uneconomical. The 1997 federal budget has widened the scope of eligible items that could qualify for tax deductions. But this still will not eliminate these extraordinary expenses.

Disincentives Arising out of Income Support. As discussed elsewhere, the manner in which income support is provided can act as a powerful disincentive to employment for many people. In some situations, individuals are allowed to earn only a very small amount before their benefits are reduced dollar for dollar. For poorly paid jobs, an individual may risk losing disability benefits as well as income and be worse off financially by working. The all-or-nothing eligibility requirement of many income support programs, which requires a person to be certified "unemployable" in order to qualify, means that a person taking a job that does not work out may jeopardize eligibility for reinstatement of benefits. Thus for many people, it would not be rational, from an economic perspective, for them to seek or to accept employment.

Attitudes. Perhaps *the* major barrier is attitudes of others, including employers, the public and administrators of government programs, including HRDC's employment programs. Much can be done with no additional expenditures. But negative attitudes and a lack of understanding result in discrimination, both overt and systemic, which serves to exclude people with disabilities from society in general as well as from the workplace. Constant rejection will take its toll on the self confidence of many people. This in turn can become a vicious circle, resulting in further lack of interaction and lack of opportunity.

Attitudes are often responsible for the lack of understanding of the costs of disability, and underlie a resistance to invest in strategies - despite their demonstrated return on investment - that can enable people with disabilities to work, such as disability management and other approaches.

ii. Lack of Coordination

As the above section states, success in employment is dependent upon other factors and the availability of a variety of other services. A number of reviews have identified the need for more coordination across program areas and across jurisdictions. For example, the 1990 Report of the Standing Committee on Human Rights and the Status of Disabled Persons (*A Consensus for Action: The Economic Integration of Disabled Persons*) pointed out the need for a comprehensive approach to "untangle the web of interconnected causes and effects."

The National Strategy for the Integration of Persons with Disabilities was developed, in part, in response to the above Standing Committee Report (Price Waterhouse, 1993). One of the primary objectives of NSIPD was to serves as a vehicle for a coordinated cross-departmental government approach. The Interdepartmental evaluation (HRDC, 1995) confirmed "the need for coordination and leadership to produce synergy and complementarity."

Nevertheless, the National Strategy was not successful in producing more coordination across departments. The Interdepartmental evaluation found a lack of sufficient consultation both across departments and with the disabled community and the provinces. It found little requirement for interdepartmental accountability, little incentive for departments to share information and inadequate communications. The evaluation concluded that; "The implementation of a coordinated interdepartmental approach requires a commitment from all participating departments to contribute to [a] shared, corporate vision."

The Canadian experience is not unique. For example, a U.S. GAO (1996a) report with the descriptive title: *People with Disabilities: Federal Programs Could Work Together More Efficiently to Promote Employment* stated:

> "Because people with disabilities often face multiple barriers to employment, including insufficient job training, lack of transportation, and employer discrimination, they may require services from more than one program to make employment feasible. . . Because services are often not coordinated among programs, people with disabilities may receive duplicate services or face service gaps."

At the *program* level, a common theme of various evaluation studies is that programs that appear to have been most successful have tended to take a holistic and individualized approach. They look at the capabilities, needs and barriers facing an individual, and develop plans that can involve the coordination of a range of services, including action by employers, arranging for accommodations, and assistance from agencies with support and on-the-job training in both employment and social skills. The GAO (1996a) identified common strategies among highly successful employment training programs for economically disadvantaged adults. These strategies include: provision of transportation, child care, basic skills training and other supports needed to enable clients to complete training and to acquire employment, strong links with the local labour market, a combination of formal training and one-on-one support.

iii. Limited Availability and Variable Quality

As this chapter has shown, rehabilitation *can* be very successful as well as cost effective in enabling people with disabilities to work. One of the biggest barriers to success with rehabilitation is its limited availability, with only a small portion of the eligible population actually receiving rehabilitation services. The amount of services people can receive often falls far short of what is needed to permit employment. It is not always clear what basic priorities are used to determine eligibility.

Again, this situation is not unique to Canada. As indicated earlier, the GAO (1993) noted that only a very small proportion of those potentially eligible actually were served by state/federal vocational rehabilitation programs. The GAO recommended a longitudinal study to explore broader issues such as who can be served, at what intensity, and with what results.

There is compelling evidence of the *potential* of various strategies, such as disability management and supported employment, to enable many people with disabilities to work. But these require effective implementation. There is limited evaluation of the effectiveness of individual programs. The GAO (1994e) indicated that few employment programs in the United States collect information on participant outcomes or study program effectiveness. The same is true in Canada.

And not all program approaches are appropriate or effective. In general, rehabilitation approaches are most likely to be effective when they are practically oriented and focused on the workplace, such as disability management and supported employment, when they take a coordinated approach, and when the individual is directly involved.

Iv. Discussion

The greatest impediments to employment of people with disabilities are *non*-employment barriers, such as lack of transportation, limited education and training opportunities, various disincentives, lack of supports, and other factors. Failure to recognize and to address these barriers results in discrimination and the exclusion of people with disabilities from the workplace. The need for a coordinated approach has been well documented, but has proved elusive at the government policy level. The National Strategy was not successful in producing a shared vision or interdepartmental coordination.

H. Summary: Major Findings and Lessons Learned

- There is ample evidence documenting the potential of many more people with disabilities (including severe disabilities) to work.

- A number of people may require supports in order to work. The all-or-nothing approach to employability, which is inherent in the criteria of many income support and employment programs, effectively excludes many people who are capable of at least some degree of employment.

- The greatest impediment to the employment of people with disabilities are *non*-employment barriers, such as lack of transportation, limited education and training opportunities, and lack of supports. Lack of supports can be a bigger barrier to employment than the degree of disability. The need for coordination has been well documented.

- Workplace accommodations can enable many people with disabilities to be employed in regular employment settings. Contrary to common perceptions, most accommodations are not costly, with half costing less than $250 and many not involving any cost.

- The cost effectiveness of vocational rehabilitation has been well documented. Disability management, where the return on investment of return-to-work strategies can be many times the investment, is particularly cost effective.

- Not all rehabilitation approaches are equally effective. Integrated approaches, which involve employers, provide necessary supports and accommodations to individuals as well as to the employers through outside agencies, and which take an individualized approach, seem to be most effective.

- The effectiveness of wage subsidies has been mixed. Other approaches, such as barrier removal, generally appear to be more successful.

- Supported employment, involving training and work at the job site with the help of a job coach, provides opportunities for people previously perceived as too severely disabled to engage in meaningful work, and can permit those who traditionally have been relegated to sheltered workshops or to day centres to do real productive work in regular employment settings. It is very popular with individuals, can facilitate integration, and is less costly than alternatives.

- The National Strategy did not succeed in producing a shared inter-departmental vision or coordination. Lack of coordination across program areas, federal government departments, and jurisdictions, has been identified as responsible for inconsistent policies, overlaps and gaps.

4. Barrier Removal Legislation

by David Baker

Barriers prevent people with disabilities from achieving their full potential for financial and social independence. Those responsible for barriers may occasionally remove them out of goodwill or out of desire to expand market share, but there is no proof that awareness campaigns and public relations campaigns have had more than a marginal impact. As a result, there is a clear international trend in all industrial, and many developing countries, to enact barrier removal legislation.

A. History

Prior to 1973, the government's role was confined to providing social programs designed to alleviate in some measure the burden of disability. Other than employment programs for disabled veterans, the private sector was not engaged in the process of inclusion or barrier removal.

At about this time, four strands came together to create the circumstances in which private sector involvement became a priority, and legislation became the mechanism for ensuring its involvement. First, human policy called for "normalization" of services (that is, offering

persons with disabilities the opportunity for lives that are as close to those of non-disabled persons as possible). Second, people with disabilities and their families become politically active and demanded to be heard by policy makers. Third, governments began to be concerned about the growth of the welfare state, making independence and private sector involvement more desirable. Finally, the experience of legislation dealing with the social disadvantage experienced by other minorities, notably members of visible minorities, provided a model to be adapted and utilized.

The first prototype of using human rights legislation to enforce barrier removal was the *Rehabilitation Act of 1973* in the United States. At about the same time building codes, which had previously addressed safety and generic convenience issues, were expanded to include accessibility standards for newly constructed buildings. These American innovations quickly found their way into Canada, with access provisions being added to building codes in the mid-1970's and generic human rights legislation being amended to include persons with disabilities amongst the protected classes between 1977 and 1982. The trend has accelerated in recent years with Australia and France introducing legislation in 1992 and Germany adding a constitutional amendment in 1994. The United Kingdom enacted legislation that came into effect in December 1996.

Apart from Canada and the United States, experience with mandatory barrier removal legislation has been limited. Nevertheless, some reference will be made to issues that have arisen in these jurisdictions during implementation.

Other industrialized countries have relied on legislated labour market policies to achieve the economic integration of persons with disabilities. These policies will be examined in the employment section of this chapter.

Later in this chapter, Canadian and American results with barrier removal is compared. As will be apparent, the major divergences occur following the enactment of the *Americans with Disabilities Act* in 1990. The Canadian attempt at a second generation anti-discrimination equivalent to the *ADA*, referred to as "Omnibus Legislation", is generally acknowledged to have been inconsequential. Mandatory employment equity legislation in Canada will be examined in the employment section of this chapter.

B. Standards

Standards that clearly prescribe the means of compliance (*prescriptive standards*) are most easily enforced, since the amount of interpretation involved is minimal. This is the approach taken in building codes, and in regulations under the *National Transportation Act*.

Debates about prescriptive standards tend to concern their sufficiency (have they gone far enough in removing barriers) on the one hand, and their rigidity (new and better technologies are available but not prescribed) on the other.

In order to avoid rigidity but ensure access, the Americans have shifted to *descriptive standards* which describe the results to be achieved in order to be in compliance. An example would be the requirement that a technology be "accessible and useable" by people with disabilities, without prescribing the technical specifications of the technology. This approach accommodates changes in technologies over time. However, debates can arise about how the standard is to be interpreted in a particular set of circumstances. In Canada, there was a decision to move to a descriptive standard for over-the-road bus accessibility in 1993, but this federal-provincial agreement has not been implemented.

Another innovation introduced by the Americans was the *conditional standard*. A business is required to meet the standard provided it does not impose "undue hardship" or it is "readily achievable". This adds a further level of interpretation which is problematic in that it depends on the subjective circumstances of the business, a condition with which a person with a disability could not be expected to be familiar. The clarity of the standard itself still makes enforcement straightforward. The business must demonstrate exceptional (and presumably temporary) circumstances which would warrant excusing it from the standard of general application.

In Canada, the standards that apply in human rights and Charter cases are far from clear. For convenience, the "discrimination" standard will be described as a *conditional formula*. Examination of the litigation record shows that few cases hinge on the condition of a business' financial means. Virtually all depend on a determination of whether the barrier is discriminatory. Notwithstanding the fact that term has been in use since the mid 1960's, it remains a matter of dispute, with the formula constantly evolving. As a result, there are very few clear precedents from which it could be said a "standard" for barrier removal had emerged. Because of the stigma associated with the term discrimination, and the low rate of success achieved by complainants, there is a strong incentive to oppose these applications. Cost effectiveness is therefore very low, as is the resulting social integration.

C. Enforcement Mechanisms

Canada has relied on generalist enforcement mechanisms: human rights commissions. Such bodies have been process rather than goal orientated. Because the standards are unclear, the costs of enforcement have been very high relative to the barriers removed.

In the United States, and all the other countries that have followed its lead in enacting disability-specific barrier removal legislation, the enforcement mechanisms are more specialized. In the United Kingdom and Australia, for example, disability-specific sections have been established in issue-specific departments or agencies

Specialization has contributed in these jurisdictions to the ability to consult credibly with both the disabled community and the business sector (transportation, for example) to which the legislation applies. Consultation has been essential to the development and periodic revision of

standards. It has also contributed to effective public education and credible technical assistance. As a consequence, the barrier removal process is much less dependent on litigation.

In Canada, experience with the Canadian Transportation Agency (CTA) and the Canadian Radio Television and Telecommunications Commission (CRTC) confirms the thesis that specialized agencies are more cost-effective at barrier removal and successful at achieving social integration (with resultant impact on labour market integration). The CTA particularly has combined a regulation initiating role with an adjudicative role, which has contributed significantly to barrier removal. However, current government policy favouring voluntary guidelines over enforceable standards has detracted from the steady progress that had been occurring in this area.

The CRTC has made significant strides in telephone-hearing aid compatibility, message relay systems, captioning of television and, most recently, accessibility of the information highway to persons with disabilities. Since most of these issues have been addressed through an adjudicative rather than standard creating mechanism, progress has been slower and less comprehensive than in the area of transportation. As well, the decisions have tended to follow and reflect legislative decisions made by the United States Congress.

D. Access to Enforcement

Public enforcement of standards tends to be the most comprehensive. This occurs most often where standards are specific and can be addressed prospectively through a licensing, permit or plan approval process. Reliance on a public enforcement mechanism is least likely to be successful where the standard tends to be a conditional formula, as is the case under the federal *Employment Equity Act*, or human rights legislation.

Canadian human rights commissions all have authority to initiate complaints, but driven as they are by backlog management, they tend not to exercise this jurisdiction. As a consequence, cases of systemic importance tend not to be litigated in Canada. In the United States, the Department of Justice has enunciated priority areas in which it is committed to achieving specific goals. It will only take on cases which are consistent with these goals, and only as many additional cases as can be handled within its allocated budget. Often these goals are systemic in nature. Notwithstanding public perception to the contrary, significant change has occurred despite the relatively small number of cases going to litigation (Dept. of Justice, 1996). A large number of cases are resolved without the need for litigation. These settlements receive publicity comparable to court judgments and are assumed to accurately reflect the law.

In the United States, the public enforcement model can permit private litigation to occur as an alternative to the public process. In the case of employment, individuals are free to pursue private remedies without even going to the Equal Employment Opportunity Commission (EEOC).

Exclusive reliance on *private litigation* can create access problems and preclude effective remedies unless the process is developed with care. The CTA has developed a user-friendly and credible dispute resolution process which resolves cases within 120 days, without the necessity of retaining counsel or conducting an oral hearing in most cases.

The CRTC on the other hand, conducts a very formal and resource intensive process. Only the most articulate and well-informed person with a disability would be able to pursue a systemic remedy without a significant expenditure.

Incentives can play an important independent or complimentary role in barrier removal. In Canada, the *Income Tax Act* provides in s. 20(1)(qq) a limited acceleration of the deduction of capital expenditures. In the United States, the *Internal Revenue Code* s. 44 provides a generous tax credit for a wider range of eligible accommodation expenses, in addition to the s. 190 accelerated deduction upon which the Canadian deduction was based. Uptake on these incentives appears to be directly related to the rate of legislated barrier removal, suggesting that legal enforcement is the primary motivator, although reduced cost may help "the medicine go down".

E. Evaluating the Impact

The evidence indicates that barrier removal is slow to non-existent without legislative action. The inter-city bus industry is the only major transportation mode in Canada not subject to legislated standards, notwithstanding virtually zero accessibility. Voluntary measures have not worked. The industry has been under threat of legislative intervention for six years with negligible impact. Not surprisingly it is the subject of most criticism by persons with disabilities (Goss Gilroy, 1995c).

There is considerable American evidence that implementation of legislated standards that are:

- specific and clear;
- developed following consultation with service providers and persons with disabilities; and
- enforced following a phase-in period during which technical and legal advice is available;

has resulted in significant progress with barrier removal (GAO, 1993a, 1994a; Gallup, 1992; UCPA of A, 1993; West, 1991, 1994, 1995). Of particular interest are the Regional Information Centres, which are regarded as credible and useful by American business. No comparable expertise is available to Canadian business outside the employment area. Likewise, no comparable Canadian success in removing barriers can be demonstrated.

There is also considerable evidence that American businesses have shifted from opposing legislation to supporting it. For example, trade associations by and large have worked co-operatively to implement the *Americans with Disabilities Act* rather than lobbying to have it

weakened or repealed (Foley, 1994). A majority of senior human resource managers found it had a positive impact on hiring decisions (Global Strategy Group, 1966). Senior executives expressed overwhelming support for the ADA, with more supporting strengthening than weakening it (Louis Harris, 1995).

Furthermore, there is also evidence of support among the public for barrier removal, including a clear willingness to pay the costs of barrier removal in a wide range of service areas (Louis Harris, 1991). A comparable survey is about to be conducted by Louis Harris in Canada.

A survey of persons with disabilities indicates a remarkable 96 per cent not only knew what the ADA was, but agreed it had already made a difference in their lives, only four years after implementation (UCPA of A, 1996). Disability organizations share this belief (National Council on Disability, 1995). The perception that change is occurring amongst persons with disabilities is considered as significant as the changes themselves (Blanck, 1995). People who had given up hope in the face of barriers they considered insurmountable, are demonstrating renewed enthusiasm to enter the mainstream (National Council on Disability, 1995, 1996).

Studies in the United States have demonstrated the *ADA's* positive impact on barrier removal by private services available to the public (GAO, 1993a, 1994a), public school boards (GAO, 1995a), communications (Strauss, 1993; Blue Ribbon Panel, 1994), the federal government (Mendelsohn, 1995) and state and local governments (Pfeiffer and Finn, 1995).

F. Employment: A Special Case

Employment is somewhat different from other barrier removal issues because:

- Employment decisions are particular to the individual employer, employee and job situation and therefore pose special problems when applying general standards;
- The issue has a close relationship with other social welfare and labour market issues (who bears the cost of disablement and do policy makers care about the lost productive capacities of people with disabilities?); and
- A person's ability to be employed depends on the removal of barriers in a number of other areas (e.g. training and education, transportation and housing) which are not necessarily within an employer's control.

For these reasons the issue merits special attention.

Virtually every industrialized country has a legislative employment program for persons with disabilities. They generally fall into two groups:

- Over-arching anti-discrimination legislation (such as the United States, Australia and Canada); and

- Labour market policies designed to ensure a pre-determined level of labour force participation (most other industrialized countries with Germany the most successful prototype).

The United States has the most highly developed and longest running anti-discrimination policy. There is also more evidence of success than in Canada. The *Rehabilitation Act of 1973* established the principle of non-discrimination and "the duty of accommodation". Prior to passage of the *Americans with Disabilities Act*, the law appears to have been ". . . of most value to people with disabilities who are otherwise well-prepared to compete in the labour market [that is, those with good educations] or purchase goods and services in the product market [the well to do]; it will do little good and may do harm to the doubly handicapped (Burkhauser et al, 1982)."

Overall, the labour force participation of persons with disabilities declined marginally from 1973 to 1990, demonstrating extreme sensitivity to fluctuations in generic employment rates. It is likely that much more dislocation would have occurred in the absence of legislation, since this was a period of restructuring. The *Rehabilitation Act* provided incentives to develop disability management programs intended to return people with disabilities to work following an industrial accident. Improved representation of some sub-groups appeared to be linked more to barrier removal in education than in employment. Qualified persons with disabilities are able to compete, with accommodation, on a more competitive basis.

While the employment rights of people with disabilities have not been substantially changed by the *Americans with Disabilities Act*, Department of Census data indicate that the employment rates for severely disabled people improved markedly between 1991 and 1994 (McNeil, 1996). This may be explained in part by the general improvement in employment rates for the population as a whole. Persons with disabilities would be expected to benefit disproportion-ately from such improvements because of their relatively marginal labour market attachment.

It must also be said that the ADA benefits identified above (clear standards, specialized enforcement, high public profile, available expert advice) are apparent in the employment field as well. Special factors would include the deterrent effect of several high profile multi-million dollar damage awards and unrestricted access to the courts (as opposed to discretionary screening by public enforcement agencies). The assurance of a hearing on the merits appears to encourage settlement rather than the delaying tactics typical of human rights litigation in Canada.

The Canadian experience, based on jurisprudence and employment data generated by Statistics Canada, offers no support for a conclusion that statutory human rights legislation has in any way improved the employment prospects of persons with disabilities. This is not to suggest that some already employed people did not enjoy the benefit of productivity-enhancing accommodations which improved their prospects of promotion. Likewise it is possible that more dislocation could have occurred without the protection of human rights legislation. The conclusions reached about anti-discrimination employment legislation in the pre-ADA period in the United States apply in Canada.

One group that appears to have clearly benefited from human rights legislation in Canada is unionized employees. Arbitration enforcing human rights legislation has proven far more effective than the public enforcement mechanism of human rights commissions. Non-unionized employees and applicants for work in unionized workplaces do not benefit.

Employment equity is a Canadian hybrid. Reference to "goals and timetables" suggests a labour market approach. However, it is actually a piece of systemic anti-discrimination legislation. Data suggesting that the federal legislation from 1986 to 1996 had improved the representation of persons with disabilities, as reported by employers, has been discredited. The small number of employers reporting improved performance were demonstrated to have adopted a broader definition of disability, producing inflated results (Abt, 1992b; various Canadian Human Rights Commission reports, Rocher Institute, 1992).

Government employment is the one area where some progress could be documented during the mid- to late 1980s. However, the downsizing of government during the 1990s appears to have disproportionately affected persons with disabilities, and reversed whatever progress had previously occurred (Ontario Public Service, 1992).

Within both public and private sectors, employment equity was found to have far more beneficial impact on women and members of visible minorities than on persons with disabilities and aboriginal persons (Ontario Public Service, 1992; various Canadian Human Rights Commission reports).

Mandatory employment equity legislation was repealed in Ontario before it was implemented. New federal mandatory employment equity legislation has not yet been implemented. It would be premature to speculate on what impact it will have. This is an area where careful data collection, based on rigid application of the statutory definition of disability, would be desirable.

The labour force participation model has shifted from a system of substantial state intervention involving quotas (enforced by criminal sanctions), reserved employment and sheltered employment, to a "redistributive" (or "grant-levy) model, typified by Germany. The state intervention model still used in the United Kingdom has been discredited as stigmatizing and ineffective (Baker, 1992; Lunt and Thornton, 1993). The redistributive model has now become the standard in Europe and much of Asia, with new countries adopting the model every year, Ireland, Belgium, Indonesia being recent examples.

France shifted to the redistributive model in 1988. Its difficulties illustrate the importance of setting appropriate incentive levels and the need for effective use of technical resources in support of integration (Lunt and Thornton, 1993; Velche 1995). Japan demonstrates that the model can lead to segregation or clusters of persons with disabilities, similar to some supported work placements within private businesses in North America (Ison, 1992). In both jurisdictions, targeting incentives or integrated job placements may be deemed desirable.

The redistributive model involves identifying a target group (usually those considered severely disabled) and offering long-term incentives to employers to include them in regular employment. The system focuses on finding and maintaining employment, rather than on removing barriers to advancement within the workplace, although it often provides substantial subsidies to cover the costs of job accommodations.

> "The financial measures appear to have three aims: to compensate for reduced productivity or costs associated with employing a disabled person; to provide a reward or bonus for taking on a disabled person; and to cover all or some of the costs of adapting the workplace or working environment to meet the circumstances of disabled workers (Lunt and Thornton, 1993)."

The schemes are "redistributive" in the sense that they shift resources from employers who are unable or unwilling to include disabled employees to those who are. The financial measures can take the form of a long-term subsidy (more familiar in a North American context) or the application of a tax or levy (in Germany and Japan, for example) when targets are not reached.

The anti-discrimination and labour market approaches would appear to benefit differing groups within the disabled community. Some have questioned whether this would not suggest that the two approaches are both compatible and complimentary (Baker, 1992; Lunt and Thornton, 1993; Hum and Simpson, 1993), since the needs of differing groups will vary.

By targeting labour market incentives on those who are deemed otherwise "unemployable" for purposes of establishing eligibility for disability-based income replacement programs, it would be possible to identify persons who are least likely to be stigmatized, and most likely to generate overall cost savings. For those who would find linking disability and reduced productivity to be unacceptable, the anti-discrimination model, improved by drawing on the experience of other jurisdictions, would appear to be the preferred option. A careful examination of potential cost savings to be derived from introducing a labour market incentives model in Canada and the willingness of those on disability income programs to consider participation in such a program would be helpful so that policy development could proceed on a better-informed basis.

G. Summary: Major Findings and Lessons Learned

- Barriers, not the disability *per se*, are the major stumbling block to full participation for most people with disabilities.

- Redistributive approaches, such as used in Germany and some other countries, provide a system of permanent incentives which can permit the stable participation of the significant minority of individuals with severe disabilities whose labour market attachment is marginal.

- Clear and precise standards, such as those provided under the *Americans with Disabilities Act*, have been demonstrated to be far more effective at barrier removal than the Canadian approach involving generalized criteria and relying on litigation for enforcement. The Canadian approach is adversarial in nature, and can develop resistance rather than support for barrier removal.

- The ADA has succeeded in generating support from the business sector and the public at large, as well as among people with disabilities. It has also been successful in removing many barriers in a number of different areas.

- The ADA experience indicates that support from the business community comes after implementation, not before. Attitudes follow behaviour.

- The availability of technical assistance, such as provided in the United States to support implementation of the ADA, results in a constructive, rather than adversarial approach, and is important in generating support and facilitating compliance.

- People with disabilities did not benefit from the former federal *Employment Equity Act*. The new *Act* relies upon a conditional formula rather than providing clear barrier removal standards. Thus one can anticipate opposition and failure comparable to the experience with Canadian human rights commissions, unless detailed regulations are enacted.

5. Disability Income Programs: Balancing Opportunity and Security

by Harry Beatty

A. Disability Income Programs In Canada

There are seven principal disability income programs (if we can extend the use of the term "program" to cover personal injury tort litigation) in Canada (Beatty, 1992). These are:

i. Social Assistance for Persons with Disabilities (SA)
ii. Canada Pension Plan/Quebec Pension Plan Disability Benefits (CPP/QPP)
iii. Workers' Compensation (WC)
iv. Long-Term Disability Insurance (LTD)
v. Motor Vehicle No-Fault Accident Benefits (MVAB)
vi. Personal Injury Awards and Settlements (PI)
vii. Income Tax Credits (IT).

These programs can be described as the major ones because they are the largest in terms of dollars and impact on people's lives. Employment Insurance sickness benefits, Veterans' Benefits, Criminal Injuries Compensation and related programs are important to claimants and recipients, of course, but are much smaller in scope.

Very significant numbers of Canadians with disabilities (and their families) are totally or partially dependent on these programs. The 1991 Health and Activity Limitation Survey reported that 683,000 Canadians with disabilities between ages 15 and 64 residing in households received some form of disability-related income in the reference year. In addition, nearly 300,000 received a medical expense credit, and more than 150,000 received the Disability Tax Credit (Statistics Canada, 1994). As shall be seen, there may be reason to believe that HALS underestimated these totals (they did not include persons living in institutions to begin with), and in any event the numbers dependent on disability-related income have increased significantly since that time. Including the dependants of persons with disabilities, it seems likely that in 1997 more than a million Canadians depend wholly or partly on disability-related income.

A full consideration of disability income systems in a society would require looking at them in the context of all other disability-related programs and benefits, including:

- assistive devices programs
- drug plans
- attendant care programs
- employment programs
- transportation systems
- housing programs

and many more. This is because essentially the same type of need may be met through an income program, a health needs program, or a service program, depending on how they are designed. For example, an individual may receive an allowance to pay for prescription drugs, or be eligible to participate in a drug plan open to the general public, or receive funding for drugs from a disability-specific program. He or she may receive a shelter subsidy through an income program, or pay reduced rent through rent-geared-to income, or live in a specialized residence for persons with disabilities. In each case the government subsidy and the support provided to the individual are essentially the same, although the mechanisms are very different and may or may not be part of, or linked to, a disability income system. (This is a major reason why meaningful comparisons of disability income programs in different jurisdictions are so difficult to make.)

Following is a discussion of each of the seven disability income programs listed above, with emphasis on their major strengths and weaknesses, as identified in evaluations and studies. (As evaluations and studies, whether by governments, business, unions, insurers, or disability advocates, usually arise because of perceived problems, it is much easier to find weaknesses than strengths from the literature.) A detailed description of the administration, funding and rules governing each system is beyond the scope of this paper. Sources of useful descriptive information, however, will be identified where appropriate.

i. Social Assistance for Persons with Disabilities (SA)

Description

Social assistance falls under provincial/territorial jurisdiction, and there are considerable differences from province to province as to how social assistance for persons with disabilities is structured. But there are significant commonalities as well, largely as a result of the *Canada Assistance Plan* which was in operation from 1966 to 95, and under which guidelines were established as part of the federal/provincial/territorial cost-sharing arrangements.

Social assistance is basically a needs-tested program, under which the needs of an individual are compared with his or her financial resources (assets and income). It is a "last resort" program for those who do not have other financial resources to meet their essential needs. As such, it is a secondary payer to all other programs. Because of its "last resort" status, typically social assistance is "fine-tuned" to assess in some detail both the needs and the financial resources of the person. This leads to detailed and complex rule-making about income, liquid assets, earnings exemptions, special needs, shelter costs, and so on. The result is often a complex set of rules that is very difficult to understand and administer fairly - a sort of "income tax in reverse for the poor".

Information Sources

According to the HALS (Statistics Canada, 1994), there were 271,100 persons with disabilities in Canada aged 15 to 64, residing in households, and receiving "social assistance or welfare".

This may, however, have been an underestimate. The total listed for Ontario, for example, was just under 80,000. The Report of the Disability Determination Project Team, part of the Advisory Group on New Social Assistance Legislation process (Advisory Group on New Social Assistance Legislation, 1992) showed the Ontario Family Benefits GAINS-D caseload as passing 100,000 in 1990, with approximately 30,000 more in the "ill-health" category under general (municipal) welfare. Some of the difference may be explained by persons in institutions receiving GAINS-D, but as HALS gave a figure of just over 16,000 for the institutionalized group aged 15 to 64, there is still a discrepancy. We might hypothesize that many people with disabilities and their families do not necessarily identify Family Benefits GAINS-D as "social assistance" or "welfare" - they call it an "allowance" or a "pension". In any event, HALS appears to give a significant underestimate of social assistance disability recipients in Ontario.

The Report of the Disability Determination Task Force just referred to contains a significant overview of the Ontario system. For example, there were a number of findings regarding the caseload (as of 1992). Single persons comprised over 75 per cent of the cases: families under 25 per cent. Only about 2 per cent of the cases were related to accident or injury: the rest were related to congenital disability, illness or disease. (The low incidence of accident or injury cases was attributed to the wide workers' compensation and automobile no-fault coverage in Ontario.) At that time, 16 per cent of cases received CPP as well and got Family Benefits GAINS-D as a "top-up". Only 2 per cent, however, were getting GAINS-D as a "top-up" to Workers' Compensation.

Only 9.5 per cent of the cases, including both single persons and families, reported any earnings at all (including earnings by other family members in the family cases). The average duration on the program was 7 years.

Disabilities were almost equally divided between mental impairments (45 per cent) and physical impairments (55 per cent). Psychiatric disorders were 25 per cent and developmental disabilities 21 per cent, and the number of learning disability cases was negligible (unless the individuals qualified under some other diagnosis or label). Half of the physical impairments were due to musculoskeletal or nervous-system disorders.

Men were 55 per cent of the caseload, while women were 45 per cent. (This was not explained in the report - a possible reason is that women are more likely to be dependent on a spouse than are men.) Those over 45 outnumbered those under 45.

The Report showed an increase in the GAINS-D caseload at a rate between 5 per cent and 7.5 per cent between 1982 and 1992. The factors listed as contributing to this caseload increase were:

- aging of the population
- increase in the Medical Advisory Board's approval rate from 40 per cent in 1984 to 63 per cent in 1991 (the MAB was decentralized, implicitly recognizing conditions in the

local economy; new conditions were recognized, such as environmental hypersensitivities; the Social Assistance Review Board reversed a high per percentage of negative decisions on appeal)

- increase in the success rate of appeals at the Social Assistance Review Board from 24 per cent in the early 80s to 71 per cent in 1991-92

- deinstitutionalisation, which helped to increase the caseload of persons with psychiatric disabilities

- an August 1991 Ministry guideline stating that socioeconomic factors were to be considered together with medical conditions

- pressure on GAINS-D to accept clients due to the low levels of general (municipal) welfare, and due to municipalities seeking to avoid costs by moving clients to the provincial system.

Caseloads have continued to grow to close to 160,000 on GAINS-D in 1996 and close to 40,000 on the "ill-health" component of General Welfare, according to an internal Ministry document provided to the author.

The Advisory Group identified principles which should govern the definition and determination of disability, related to fairness and efficiency. Some of the points emphasized were: that the social assistance system should contain a "disability top-up" which was not necessarily permanent; that persons with cyclical illnesses (like multiple sclerosis or manic-depressive illness) should not be excluded unfairly by duration requirements; that the disability definition should not be a barrier to self-sufficiency; that the determination process should be equitable to persons with all types of disabilities, and that there should be an interdisciplinary approach to determining eligibility.

The Advisory Group also set forth a brief discussion of comprehensive disability income reform proposals.

There is very little meaningful comparative information on social assistance for persons with disabilities in Canada. Comparisons of maximum rates, for example, tell us very little about the real effect of the programs. The Disability Determination Task Force provided a brief comparison. One study which goes beyond this from a critical consumer perspective is Sherri Torjman's *Income Insecurity* (Torjman, 1988). Aside from Ontario, Alberta and British Columbia have what are in effect separate social assistance programs or entitlements for persons with disabilities. Torjman includes New Brunswick in this group as well.

British Columbia has recently gone through a process of reviewing its program and adopting a new definition. This was largely in response to representations from organizations representing

the disability community: major disability organizations had developed a position advocating a functional definition of disability which would not serve as a barrier to independence (Ad Hoc '95).

Strengths

The most important positive feature of social assistance for persons with disabilities is that it is available to all adults with disabilities resident in Canada as a last resort. It is the last line of defence against extreme poverty for this community. In many provinces and territories, the SA program for persons with disabilities is more adequate than SA for other disadvantaged groups.

The detailed rule-making available under social assistance arguably allows difficult questions of equity, need and social policy to be addressed, such as support for dependents, exemption of the principal residence as a liquid asset, earnings exemptions, and many more. As a needs-tested program SA is highly "targeted", so its resources can be seen as directed to those who need them most. For the same reason, SA eligibility can be used as a criterion of eligibility to other essential programs - drug and dental costs, rent-geared-to-income housing, and legal aid, to take three examples. (Of course, disability organizations typically argue for *universal* access to programs, without taking income or assets into account, for reasons discussed below under "Weaknesses". However, cost-conscious governments at all levels are moving in the opposite direction - for example, the federal Government with respect to both childrens' and seniors' benefits).

The costs of administering social assistance tend to be very modest - less than 10 per cent of the total costs of the program. However, there may be false economies here - in Ontario, workers may have caseloads of several hundred, which has led both to inadequate monitoring of cases (so that those who are really ineligible receive benefits) and to delays and lack of support which have adversely affected many clients.

Weaknesses

The major weaknesses of SA as a disability income program are essentially inverses of its strengths. Because it is a "last resort" program, it is subject to an expanded caseload, particularly during a recession, as people have no where else to turn (as was found by the Disability Determination Task Force discussed above). This is especially true of "over 50" workers with health problems, who often have no realistic prospects of employment. The expanded caseloads lead, in turn, to cost pressures on the program, and to proposals to limit eligibility either through changes in definition or in the determination process and guidelines. The result may be that people who need SA may find themselves ineligible, and be forced onto general welfare programs as a last resort.

Other weaknesses have been identified by analysts such as Torjman (1988).

The complexity of SA makes it difficult to understand, both for clients and government officials, and extremely difficult to administer. The detailed rules aimed at fairness may wind

up creating the opposite result, where two applicants or recipients in essentially the same circumstances are treated very differently (where they have "outside" income from a different source, for example).

Most significantly, the "targeting" under SA too often means that individuals are penalized for efforts to become more independent and self-sufficient. The SA disability recipient who works will have his or her allowance reduced (usually by 75 per cent of earnings or more), and, even worse, risks losing his or her "categorical eligibility". If someone tries to work and then loses the job for whatever reason, he or she may be much worse off than someone who never tried to work at all. The work disincentive in SA is probably its most criticized feature. But other efforts to become more independent - from saving to buying insurance - may also be penalized by a partial or total loss of benefits under SA.

Torjman discusses the "Catch 22" situation created by a "permanently unemployable" test of eligibility. On the one hand, recipients are required to define themselves as "unemployable" in order to at least partially meet the costs of living with their disabilities. On the other hand, it keeps them "on the system".

ii. Canada Pension Plan/Quebec Pension Plan Disability Benefits (CPP/QPP)

Description

CPP and QPP disability benefits are nearly universal programs for employees and self-employed persons in Canada, with minimum requirement of contribution of 2 of the last 3 years or 5 of the last 10 under the current plan, and 4 of the last 6 years under the new CPP proposals. Under CPP/QPP, disability pensions are paid to former contributors who, because of a "severe and prolonged disability" are "unable to regularly pursue any substantially gainful employment". The eligibility of contributors turns on their history of contributions to the CPP/QPP, including actual contributions made by the individual, "deemed" contributions through credit-splitting, and contributions made to the national pension plans in other countries with which Canada has a social security agreement. The amount of the pension is based on a flat-rate component and a component based on contributions. There is also a benefit for dependent children of the disabled contributor. CPP is a primary payer from which other disability income payments are not deducted (QPP, however, is a secondary payer to that province's workers' compensation system). There is no financial eligibility test in CPP/QPP.

Information Sources

CPP/QPP disability pensions are described fully in pamphlet publications put out by the federal and Quebec governments. An intensive evaluation of CPP, including several background studies, has been undertaken in the past two years by the Government of Canada (HRDC, 1995c; HRDC, 1996a). The results of the evaluation are fully documented in the Final Report of the Evaluation and will not be repeated here.

Strengths

The Final Report of the HRDC evaluation cited identified a number of strengths of the CPP disability pension program. These include:

- Virtually universal coverage to employees and the self-employed.
- Minimum protection for those who might not be able to afford private coverage.
- An important source of earnings for disabled persons.
- Relatively constant adjudication of applications for benefits.

These are all important points. From the consumer perspective, the fact that CPP is available without an income or asset test (either individual or family based) and that it is not reduced by other payments is important. An example is someone who becomes ill but does not have LTD or WCB coverage, and who has a spouse with a modest income or assets which makes the family totally ineligible for SA. Many who become unable to work, especially those previously in lower-paying, contract or self-employed jobs without benefits, are eligible *only* for CPP. This group includes a disproportionate number of those in groups traditionally disadvantaged in the workforce, including women, persons already disabled, visible minorities, and First Nations people.

CPP/QPP disability is also relatively straightforward, compared to many others, to understand and administer (even though caseload increase has caused significant problems for the Government of Canada). There is no income or asset testing, no assessment of need, and no determination of family status involved. Pension levels are calculated using Revenue Canada data, as are contributions (although the additional rules relating to contributions - child-rearing drop-out, credit-splitting, contributions in other countries with which Canada has a Social Security Agreement - bring a considerable measure of complexity into the system).

The costs of administering CPP are, like other public systems, relatively low in relation to benefits. The CPP evaluation conducted by HRDC would seem to imply that some additional resources would facilitate a better administrative process. From the consumer's perspective, it would also address the delays that cause problems for individuals.

Weaknesses

The universality of CPP disability benefits coverage has been reduced by the recent (1997) introduction of legislation calling for a more restrictive eligibility rule (from 5 of the last 10 years, or 2 of the last 3 years, to 4 of the last 6 years). While this can be argued to be fairer, requiring a more substantive attachment to the work force, it also tends to exclude those who may be in most need of disability income protection - new workers, contract workers, those who have been unemployed, and those who have interrupted work histories due to cyclical or progressive illnesses.

The HRDC evaluation concluded that the "CPPD administration has been relatively constant in its adjudication of applications for benefits" and that "there is no evidence that more generous

CPPD adjudication resulted in inappropriate increases in grants". Nevertheless, the evaluation also identified as a potential problem CPPD's "scope for discretionary judgment". It is clear that categorical eligibility for CPP disability has already been narrowed by administrative action. This is positive from the cost-limitation viewpoint, but there is concern in the community of people with disabilities that those who realistically cannot work will nevertheless be found ineligible. The Ongoing Case/File Review, as recommended by the evaluation, would be an important tool for monitoring the consequences of the new administrative approach.

The HRDC evaluation found, based on a Statistics Canada survey of CPP disability beneficiaries who responded (although the response rate was not as good as could be hoped), that "a significant proportion (10 per cent) may have the potential for vocational rehabilitation and return to the work force". As discussed in Section 3.B (Disability Management), the review of the National Vocational Rehabilitation Program showed the same. There is little doubt that the rehabilitation initiatives under CPP could be strengthened, and that this would generate considerable cost savings. However, from the consumer perspective, there is great concern that a person who undertakes rehabilitation or return to work, but is unable to keep a job, will nevertheless be found categorically ineligible. From this all-or-nothing approach, the design and regulations of CPP disability benefits has a very significant work disincentive effect. This is an important contributing factor to its low return-to-work percentage among recipients (less than 1 per cent annually, although virtually every CPP disability recipient has been in the work force and many have very extensive employment histories).

Like SA, CPP/QPP is susceptible to caseload increase in times of recession, especially among older workers with health problems who are effectively excluded from the job market. This was clearly identified in the CPP evaluation.

iii. Workers' Compensation (WC)

Description

Workers' Compensation is a broad, but by no means universal, system of disability income protection for employees covering accidental injuries or occupational diseases arising out of employment. It is within federal, provincial, or territorial jurisdiction, depending on the business or industry, although the federal government covers only about 10 per cent of employees and the administration of WC for federal employees is often delegated by agreement to the provincial WC administration. Depending on the jurisdiction, specific businesses or industries may be listed as included or excluded from coverage. The coverage is largely compulsory and on a no-fault basis, although there are exceptions (such as optional coverage for some businesses, limited or no coverage for employees who are injured because of their own serious misconduct). Benefits vary greatly among jurisdictions but typically include income benefits (temporary and long-term, total or partial), rehabilitation, medical care and other health needs, death and survivor benefits.

Information Sources

A text that covers Workers' Compensation in detail is *Workers' Compensation in Canada* (Ison, 1989). It covers the common features and differences among the various provincial schemes.

Statistics Canada publishes data on work injuries, based on WCB information. For 1994, a rise in work-related time-loss injuries was reported after four previous years of decline. The total number of claims in Canada for 1994 was 429,000. The increase was attributed basically to an increase in number of hours worked and an increase in the size of the work force. These data, however, do not reflect the number of long-term injured workers.

The range of issues involved in the Workers' Compensation system were reviewed in depth in Ontario in the early to mid-1980s by Professor Paul Weiler of Harvard University. His series of three reports prepared for the Ontario Government (Weiler, 1980, 1983, 1986) are an excellent starting point for an evaluation of the WC system. Weiler recommended the following:

- a higher level of earnings coverage so that the program would be more nearly universal;
- a dual award system, with one component based on wage loss and the other on non-economic loss (pain and suffering), to reflect the real losses due to disability;
- a strong emphasis on rehabilitation and return to work, including a right to return to work (subsequently enacted in Ontario as in Quebec, but in few other jurisdictions);
- an independent appeals process with support for independent advocacy; and
- a strong on-going program of prevention of workplace injury and disease.

The broad outlines of Weiler's proposals, while controversial, were accepted in Ontario. In his second report (Weiler, 1983), he advanced a thoughtful analysis of the prospects for a comprehensive disability compensation plan. He also dealt in depth with occupational illness and with prevention. In his third report (Weiler, 1986), he examined the issues related to the compensation of *partial* disability in great depth.

In 1995, the Queen's University Industrial Relations Centre released a volume of research studies on WC (Thomason and Chaykowski, 1995). This contained rigorous studies based on data from WC Board in Canada, and compared the results to United States studies in particular.

One interesting study (Gunderson, Hyatt and Law, 1995) looked at re-employment and accommodation requirements under WC. They found that re-employment requirements, such as those enacted in Ontario, are "quite rare". These requirements are not found in the United States and are not enforced in the European countries which have them. They are really a "subset" of human rights accommodation guidelines.

The authors review several studies (mainly United States studies which show there are "*potential* adverse work-incentive effects of high income replacement" as exist in WC, unlike most other programs). However, these studies are inconclusive as to the *actual* impact on individuals' decisions to return to work if appropriate rights and accommodations are provided. A second study in the same volume (Thomason and Pozzebon, 1995) shows from Canadian data (like several United States studies they cite) that increasing WC levels increases the likelihood of a claim (based on national WC data).

The authors then look at the cost of accommodations, as an alternative to income support, but are unable to draw firm conclusions based on available evidence. They state that "unfortunately, there is little systematic evidence, especially in Canada, of the cost of accommodation". It is very difficult to study this issue accurately, according to the authors, as some accommodations may be "no cost" (such as flexibility of other employees in sharing or trading job responsibilities) and other accommodations may simply not be documented because they are seen as too "high cost" and are never carried out.

An important question is whether the costs of accommodation are born by employers (or their customers), or shifted to employees with disabilities (usually in the form of lower wages and benefits). The relevant Canadian study, according to the authors, is a PhD dissertation (Hyatt, 1992) based on Ontario WCB statistics. The authors say that Hyatt's results were somewhat as expected. Where the injured worker returns to the accident employer, there is no wage reduction (in fact, an average 1 per cent increase!), presumably reflecting both rules and perceptions which would make it unacceptable to impose a pay cut. On the other hand, where the individual with a disability returns to *another* employer with no prior responsibilities, the wage reduction is around 30 per cent, three-quarters of this reflecting reduced physical demands (that is, the person can now only do a less demanding job), and one-quarter reflecting the cost of workplace accommodations (the employer has to accommodate the person so pays less).

Another study in the same volume (Allingham and Hyatt, 1995) shows a link between vocational rehabilitation services and return to work for injured workers. However, the authors state that real effectiveness is difficult to measure because of the "estimation strategy" (basically, that the workers who pursue vocational rehabilitation may have been better prospects to return to work anyway and have self-selected).

An Ontario Task Force (Workers' Compensation Board, 1987) provided detailed recommendations on vocational rehabilitation within the WC system.

Strengths

Workers' Compensation provides a moderate to relatively high level of income replacement (a maximum of $17,000 to $35,000 per year, depending on the jurisdiction) to injured workers considered to be *totally* disabled either temporarily or permanently. The income benefits are tax-free. There is also a range of additional rehabilitation and health benefits.

Of the dollars collected in WC premiums, approximately 90 per cent are spent on benefits, rather than administration.

WC premium-rating systems, which charge employers in higher-risk industries or with poor safety records more for coverage, can play a role in encouraging prevention.

In some jurisdictions, such as Ontario and Quebec, some success has been achieved through return-to-work legislation supporting return to work to the employer where the accident occurred.

Weaknesses

From the employers' and administrators' perspective, the rate of earnings replacement for total disability is too high to encourage return to work. The research reports referred to above provide some support for this position, although it is somewhat inconclusive. WC clearly provides a higher level of income replacement than do most other disability income programs. Ontario has recently reduced the level of income replacement, and this might provide an opportunity to study the impact on injured workers and return to work.

WC has been funded more on a pay-as-you-go than a full actuarial basis in some provinces, which has led to a significant unfunded liability. From the employers' perspective, this is an unfair transfer of costs from past claims to future years, while from the injured workers' viewpoint, this leads to significant pressures to reduce benefits, which has occurred in recent years in several provinces.

Both employers and workers have been critical of the rehabilitation programs of the WC Boards in a number of Provinces. An underlying problem is that the WC Board delivers both income replacement and rehabilitation, which may lead to a confusion of objectives. The 1987 Ontario Task Force looking at vocational rehabilitation within the WC system emphasized that "the structure of the WCB must be changed to separate the function of claims and rehabilitation and rehabilitation must be made a full partner in the process" (Workers' Compensation Board, 1987, p. 62). Otherwise there is at least a *perception* on the part of the injured worker that rehabilitation is being offered as part of a claims-control process - hardly a sound basis on which to build an effective vocational rehabilitation plan. WC (and other disability income program deliverers) must of course be heavily involved with rehabilitation, having a strong interest in its success. But the rehabilitation program must be seen as relatively independent of claims adjudication.

From the injured workers' perspective, a major problem is that those with long-term partial disabilities often receive very low pensions which do not really reflect their disadvantage in the labour market. This is especially true of older workers who are unable to continue at strenuous labour, but cannot adapt easily to other employment because of factors such as limited education and language barriers.

The difficulty of proving a causal relationship between workplace environmental factors and occupational illnesses is also a significant problem (as discussed in depth by Professor Weiler in the study referred to above). For example, the link between substances in the workplace and cancer is very difficult to establish in practice, even though there may be a theoretical basis for it, because decades may intervene between the exposure and the disease it may have caused. Of course, this creates a funding problem for WC Boards as well, since significant recognition of occupational diseases would add to the unfunded liability problem.

iv. Long-Term Disability Insurance (LTD)

Description

Long-term disability insurance is most commonly available in Canada as a benefit provided by employers on a group basis. The coverage is usually provided by an insurance company, although some large employers self-fund their plans and pay an insurer to administer the plan. Coverage can also be purchased on an individual basis or through professional groups.

LTD provides coverage for disability arising from any cause during the contract period, most commonly on a "permanently unemployable" basis. A typical clause provides coverage for someone who is unable to do his or her "own employment" during the first two years of disability, but thereafter only for someone who is unable to do "any employment for which he or she is reasonably qualified by age, training and experience". Earnings replacement is in the range of 60 to 70 per cent of pre-disability earnings, commonly without indexation (except in the government sector). A common additional provision is a "cap" in the 85 per cent range on disability income from *all* sources. LTD is almost invariably a secondary payer to CPP disability and WC. Some policies, but by no means all, have rehabilitation and partial disability provisions. LTD payments are taxable where employers pay the premiums but non-taxable where employees or individuals pay the premiums.

LTD falls under provincial and territorial jurisdiction. Unlike government programs and automobile insurance no-fault benefits, however, the provisions of LTD coverage are not regulated closely by government — employers and insurers have considerable latitude in determining the coverage provided. The Canadian Life and Health Insurance Association (CHLIA) is active in developing LTD guidelines, but policies vary considerably.

Information Sources

Because of its variability, there are few detailed resources available with statistical information about LTD. Some basic facts are available from the Canadian Life and Health Insurance Association - for example, it publishes a basic pamphlet on LTD (Canadian Life and Health Insurance Association, 1992).

Some overview information is contained in articles in periodicals such as *Benefits Canada*, which conducts an Annual Review of Group Insurers. The Benefits Canada Annual Review for

1995 (Bak and Dempsey, 1996) surveyed 44 insurers, and found an 8.1 per cent annual increase in "group health" premiums (the term "group health" appears to cover extended health benefit plans as well as LTD). The article, however, goes on to describe the major concerns to insurance providers as being "skyrocketing" claims, especially in late 30s and early 40s workers with non-physical disorders, according to one company executive. Stress, chronic fatigue syndrome and depression are identified as particularly increasing claims. As well as cost containment, cost shifting from the public to the private sector and taxation of benefits are identified as important issues for insurers (although the latter presumably relates to extended health benefits rather than LTD).

The 1991 IIALS survey reported 32,615 Canadians with disabilities receiving income from a private disability insurance plan, and 71,715 from an employer disability insurance plan.

Professor Marvin Baer of the Faculty of Law, Queen's University, recently completed a (draft) study of the legal issues involved in long-term disability insurance for the Ontario Law Reform Commission (Baer, 1996), but as the OLRC is now defunct the status of this study is uncertain. Professor Baer made a number of recommendations directed at better protection of clients in the system. One important recommendation was that an Alternate Dispute Resolution system be introduced so that claimants involved in disputes with insurers would not necessarily be involved in the expense of litigation.

A good overview description of LTD and issues related to its use and effectiveness is found in *Illness and Disability in the Workplace* (D'Andrea, Corry and Forrester, 1996). Some of the case law up to 1992 has been covered by Michael Kelly in his article "Taking on the Terminator: Issues to Consider When Suing A Disability Insurer" (Kelly, 1992).

Strengths

LTD is flexible — employers can negotiate coverages that are suitable for their employees.

LTD is the primary system available to provide an adequate level of income replacement to higher-income employees for disability regardless of cause. This is its overriding importance to employers, employees, and the self-employed.

Some LTD insurers have been innovative in their use of rehabilitation.

LTD is essentially on a "full-funding" basis, so underfunding is less of a problem than in government plans (although insurer insolvency can result in recipients losing some of the value of their payments, as happened in the Confederation Life case).

Weaknesses

LTD is unavailable or practically unaffordable to many in the workplace. Those in lower paying or contract positions typically do not have LTD. Small businesses cannot afford it. In our changing economy, LTD coverage is becoming available to fewer and fewer employees.

Unlike government programs such as CPP/QPP, LTD excludes or limits coverage for those with "pre-existing" disabilities, or makes coverage available only at a higher cost. This limits the employment and re-employment prospects of persons with disabilities. For example, someone who acquires an ongoing progressive disability, such as multiple sclerosis, while with one employer cannot risk changing employers, since disability due to multiple sclerosis would be a "pre-existing condition" exclusion under the new employer's LTD plan.

The lack of inflation protection in most LTD plans is a major problem for younger employees who become disabled, especially when combined with a modest level of total earnings replacement and taxable payments (which is most common for employees).

From the claimant's perspective, if a dispute arises with the LTD insurer it is very difficult to pursue a claim. It is necessary to sue the insurer civilly, which costs significantly in legal fees and delay, just when the person has already incurred a loss of income and, in many cases, increased personal expenses due to disability.

Some insurers take a very restrictive approach to rehabilitation - although, as already noted, others are very progressive.

v. Motor Vehicle No-Fault Accident Benefits (MVAB)

Description

It is difficult to describe MVAB generally in Canada because there is so much variation amongst provinces and territories. Compensation for motor vehicle accident injuries is balanced in different ways between MVAB and personal injury lawsuits (discussed next), depending on the province. Quebec, alone of all the provinces, has replaced personal injury tort litigation entirely with a public MVAB. Alberta and the Maritime provinces still have primarily a personal injury litigation system, with limited MVAB for those who can't sue a negligent party. Ontario, and to a lesser extent, Manitoba and Saskatchewan, have produced "hybrid" systems which combine MVAB and tort litigation in various "balances".

Automobile insurance is public in British Columbia, Saskatchewan, Manitoba and Quebec, and private in the other provinces and territories. As may be seen from the above, there is no necessary link between public insurance and a "no-fault" approach, although in general they may be seen to be more compatible.

MVAB coverages are typically defined in detail by the provincial governments responsible, although there may be optional coverages. As well as income replacement, rehabilitation, health and care costs are typically covered, although much more under MVAB in provinces like Quebec and Ontario than in the provinces which still have primary reliance on personal injury litigation.

Information Sources

The Insurance Bureau of Canada (IBC) is the major source of information regarding automobile insurance. Its publication "Facts of the General Insurance Industry in Canada" summarizes the coverages available in the provinces and territories (Insurance Bureau of Canada, 1996). This publication shows an overall picture of rapidly increasing costs for injuries due to motor vehicle accidents. Total claims throughout Canada for private insurers increased from $2.657 billion in 1983 to $7.173 billion in 1995, on a more-or-less steady basis. This includes property damage as well as personal injury, but personal injury is the largest component and is increasing the fastest. Private insurers in 1995 had close to 110,000 no-fault accident benefits claims. No separate statistics are provided for third-party bodily injury claims, but Appendix "B" of the publication shows a sharp increase in third-party liability claims during 1991-1995, of which bodily injury is a major component. The IBC summary does not include the government insurers in British Columbia, Saskatchewan, Manitoba and Quebec.

The 1991 HALS reported only 12,205 Canadians with disabilities receiving payments from Motor Vehicle Insurance, but it is difficult to accept this as accurate given the figures just cited. As noted in the next section, HALS did not cover third party liability settlements and awards, whether arising from motor vehicle accidents or otherwise (Statistics Canada, 1994).

An excellent summary of the policy issues involved in different models of automobile insurance is found in *The Crisis in Insurance Regulation* by Banks McDowell (1994). Although this is an American study, the author covers the Ontario and British Columbia systems. McDowell advocates a minimum or "first" level of coverage provided by government insurance and excess coverage provided by private insurers on a "second" level (optional to clients). He reviews briefly and clearly the issues involved in balancing tort/no-fault and government/private, the two "great debates" in automobile insurance (often confused by the public).

Two major Canadian automobile insurance texts are Brown (1988) and O'Donnell (1991).

There have been numerous detailed studies of the automobile insurance system in Ontario and of the various options. Of particular importance are the "Report of the Inquiry Into Motor Vehicle Accident Compensation in Ontario" (Osborne, 1988) and the Ontario Automobile Insurance Board no-fault reference hearings (Ontario Automobile Insurance Board, 1989), each of which examined the issues in great depth. (The Ontario Government, however, moved more in a no-fault direction for automobile insurance than either of these studies recommended, primarily because each study had underestimated the rapid cost increases that were occurring in third-party litigation.)

Strengths

MVAB is generally assessed in relation to personal injury litigation, with the perspective of the assessor on tort influencing the result greatly.

Supporters of a "no-fault" approach argue that benefits are provided much more quickly, and with less administrative costs, than under personal injury litigation. Typically there is a tribunal or alternative dispute resolution (ADR) system for MVAB, which is more accessible than the courts. (This position was very strongly advanced, for example, by the Consumers' Association of Canada in the Osborne inquiry and the Ontario Automobile Insurance Board reference hearings.)

MVAB, which is on a no-fault basis, compensates many persons injured in automobile accidents who are not compensated in the tort system. This includes drivers who were themselves at fault in their accidents (except that there are typically limitations or exclusions in coverage for particularly serious offenders, such as drunk drivers), but also includes those whose conduct was relatively blameless but have no other driver to sue, as would be the case with a single-vehicle accident caused by bad weather conditions.

Weaknesses

Critics of an MVAB "no fault" approach to automobile accident compensation generally approach it, as already noted, from a "pro-tort" perspective.

MVAB, with limited exceptions, compensates regardless of "fault". In comparison to tort, it tends to compensate "innocent victims" less generously and "at fault" drivers more generously, which may be less just than the personal injury tort system.

As well, MVAB may have less of a deterrent effect on bad driving than tort - although other factors such as law enforcement and driver education and licensing clearly are also closely linked to accident prevention.

vi. Personal Injury Awards and Settlements (PI)

Description

As noted in the discussion of MVAB, the largest number of personal injury cases still arises from motor vehicle accidents (except, of course, in Quebec where such cases ave been eliminated). But many other causes of injury or illness lead to personal injury tort litigation - "slip/fall" accidents, product liability, sexual assault cases, and so on. Medical malpractice actions are particularly prominent in public attention, and may lead to the largest awards or settlements of any personal injury cases, although only a relatively small number succeed in Canada.

The rules governing civil litigation, including personal injury actions, are in provincial/territorial jurisdiction.

Information Sources

Little comprehensive information is available to provide an overview of personal injury litigation in Canada. Most "evaluation", as already indicated, is on a partisan basis supporting either the "tort" or the "no-fault" side of an on-going debate - and the debate is conducted almost exclusively by law professors and lawyers.

An important study related to medical malpractice in Canada was conducted on behalf of the Conference of Deputy Ministers of Health by Robert Prichard. Entitled "Liability and Compensation in Health Care" (Prichard, 1990), this report recommended implementation of a no-fault compensation scheme for health care injuries, based on a Swedish model. The right to sue for medical malpractice would not be abolished: at some point, however, the individual claimant would have to choose between the two forms of compensation. While medical malpractice litigation is only a small component in the overall picture of disability compensation, there is nevertheless a considerable amount of valuable policy analysis in the Prichard study.

Strengths

The perceived strengths and weaknesses of personal injury tort litigation are really the inverse of those for no-fault disability compensation like MVAB. Briefly, the important strengths of tort are:

- Justice is seen to be done through a full hearing of the case in a court of law.

- In theory, compensation for the "innocent victim" is on a full restitution basis, in which the plaintiff is compensated fully for all disability-related costs caused by the wrongdoer (in practice, however, the level of compensation is limited by factors such as the insurance or other funding available).

- The threat of civil litigation is argued to be a deterrent to intentional wrongdoing, unsafe practices, and negligence - for example, companies are forced to make their products safe by the threat of litigation.

Weaknesses

The major perceived weaknesses of the personal injury tort system are:

- The administrative costs of the system - lawyers' fees, expert witnesses, court administration and so forth - are high in relation to the compensation actually provided to persons with disabilities.

- There are very significant obstacles to many persons with disabilities in accessing the personal injury tort system, especially cost (for example, the risk of paying adverse costs if the plaintiff loses) and delay.

- A person with a very significant disability which is theoretically compensable in tort may be unable to get full or adequate compensation because of limited available insurance or other funding, or because of difficulties in proving the case, as in an accident without witnesses.

vii. Income Tax Credits (IT)

Description

There are several provisions available in Canada's income tax system that can benefit persons with disabilities. The two principal ones are the Disability Tax Credit (DTC) and the Medical Expense Credit (METC).

Information Sources

These claims are described in detail in several materials published by Revenue Canada, most notably Interpretation Bulletin IT-519R (Revenue Canada, 1995). Tax expert David Sherman reviews all of the claims in great detail in *Taxes, Health and Disabilities* (Sherman, 1995). The Disability Tax Credit was evaluated in detail by the Department of Finance (Department of Finance, 1992). Most recently, the entire range of disability-related tax claims was reviewed by the Federal Task Force on Disability Issues (1996).

Income tax is practically in federal jurisdiction - only Quebec has its own tax return - but the provinces basically share the costs of these credits through the provincial income tax that is foregone.

Strengths

The DTC and METC (and the other IT claims) are administered on a cost-effective basis through the income tax system. They do not require a separate administration. Delivery through the income tax system permits widespread eligibility and accessibility of the claims.

Together, the DTC and METC provide the beginning for a comprehensive approach to recognizing the costs of disability, with DTC covering non-specific, incidental, and "hidden" costs, while METC covers identifiable and specific expenses. They are supplemented as well by the other IT claims.

Weaknesses

There are major issues around eligibility for the DTC. The Government is concerned to limit eligibility to those most in need (see especially Department of Finance, 1992), while disability organizations believe that eligibility is being denied those with significant disability-related disadvantages and costs.

The DTC provides the same level of payment to everyone who qualifies, assuming they can make full use of a non-refundable credit. It could be criticized from this perspective as not being effectively targeted to those most in need. However, "fine-tuning" would require more categories or some other type of individualized assessment, and the administrative costs necessarily entailed by this would probably outweigh the gains in equity, which are extremely difficult to define and measure in any event.

The METC excludes a number of items that are legitimate disability-related costs: measures were announced in the 1997-98 Federal Budget to begin to address these.

There is also a major issue around non-refundability of the DTC and METC. Disability organizations criticize this feature as denying financial support to those members of the community most in need, while Government tends to view refundability as a form of delivery of social programs - which is provincial jurisdiction - and thus not appropriately placed within the tax system.

B. Lessons Learned From Evaluations And Reviews Of Disability Income Systems

All the disability income systems discussed in the previous section have been the subject of major policy reviews in Canada during the past decade. In most cases, significant restructuring has followed the policy reviews. Despite the scrutiny these systems have been under, however, great caution must be exercised in identifying "lessons learned" from policy reviews and evaluations.

One major reason for this caution is that detailed reviews have tended to focus on disability income systems "one at a time", without considering their interrelationships, which can give a very misleading picture of what is happening. For example, if the eligibility criteria under one disability income system are made more restrictive, people with disabilities who otherwise would have qualified for it typically wind up claiming from another system.

Two examples may illustrate this. Automobile insurance, and in particular premium increases, are a political "hot topic". When the Ontario government reviewed automobile insurance and brought in a new system in 1990, automobile insurance was made a secondary payer to LTD, a system which attracts much less public attention. But there is no real logic to or cost-saving created through reversing the priority of two programs in this way. Why should LTD group insurance plans be first payer for a motor vehicle accident?

Another example (discussed in the HRDC CPP evaluation) is the Ontario government's implementation of an initiative to require all social assistance (Family Benefits) recipients to apply for CPP. While some recipients might benefit from CPP eligibility, others were "losers" because CPP is taxable while SA is not, a factor not taken into account by the provincial government for a person in both SA and CPP. Thousands of recipients received essentially the same total amount from government as a result of this process, and the only real result was a

"shifting" of costs from the provincial to the federal level. The interrelationships among the different disability income systems are dealt with in the next section.

Nevertheless, some major themes and lessons emerge from the various reviews and evaluations. As pointed out in Chapter 2, the definition of "disability" for eligibility purposes has become a major contentious issue in virtually every system. From the perspective of those funding the systems, primarily governments and insurers, it is essential to ensure that eligibility standards are strictly enforced so that costs are controlled and benefits delivered to those who truly qualify. This direction may be reflected in the use of qualifiers like "severe" in defining disabilities, or in requiring that qualifying disabilities be "prolonged".

From the perspective of persons with disabilities, on the other hand, the primary concern is that those who are in need, looking realistically at their disability in the context of their life situation, receive or continue to receive income support. Disability advocates and organizations are opposed to definitions which use standards such as "severe" and "prolonged" to limit eligibility, especially when this is combined with a policy of disregarding or de-emphasizing the social and economic factors that may interact with and add to the consequences of disablement, such as age, lack of education, and language barriers.

Closely related to the "disability definition" issue is the fundamental dilemma usually known as the "welfare trap" or "work disincentive" problem. In the disability income systems reviewed in the previous section (except for Income Tax credits), an important component of the existing definition of disability is that the individual be unable to work, at least on a long-term, if not a permanent, basis. This criterion of eligibility makes sense, of course, in that the very purpose of disability income systems is to provide an alternative source of income to those who are "unemployable" because of disability.

But, as a consequence, people with disabilities who may have significant potential for employment face the prospect of losing their disability income eligibility *entirely* by undertaking rehabilitation, training, education or returning to work. If they are found to be no longer "unemployable", they may lose their "categorical eligibility" for assistance from the disability income systems, perhaps forever. Reviews and evaluations inevitably identify this "welfare trap" as an issue of central importance, but are equally inevitably *unable* to identify solutions. So the critical "lessons learned" are (a) this is the most critical problem to address and (b) it is extraordinarily difficult to address this problem efficiently and equitably — to "balance opportunity and security", as the title of this chapter states.

The potential for people with disabilities to be employed is discussed in Chapter 3. When a person with a disability is employed, and becomes a contributing, taxpaying member of society rather than dependent on a disability income system, this is a "win-win" result. Everyone benefits. The possibility of cost-savings to the system funders are enormous. And, of course, the benefits to the individual, both financial and personal, can be tremendous. But the "welfare trap" is an enormous obstacle to this happening. Report after report in Canada, at both the federal and provincial levels, has shown a poor record of return to work by disability income system recipients. It is important to look more closely at why this is so.

A starting point is that "unemployability", and its inverse, "employability", are "all-or-nothing" concepts. A system based on "unemployability" as a key definitional concept is, in effect, assuming that persons with disabilities can be neatly divided into those who can work and those who cannot. In reality, however, a very significant percentage of persons with disabilities falls into a "gray area" between the two. Some can work, but only part-time. Some could work if barrier removal and individual accommodation were in place. Some could work if only they had transportation. There is a whole range of individual circumstances. But if any prospect of long-term security is to be maintained for the individual and his or her family, our "system" usually pressures the person (and his or her health advisors and advocates) to maintain status as an "unemployable" person. Otherwise he or she risks, not only the loss of long-term income security, but also other consequential benefits, such as drug coverage and rent-geared-to-income housing.

What appears to be needed is a more flexible approach to eligibility for disability income protection, which will take into account significant disadvantage in employment, even where that disadvantage has been successfully overcome for an extended period. This more flexible approach should also allow for continued eligibility for those able to work only part time or on a periodic basis. Continued eligibility for drug and other essential health benefits should, in particular, be ensured for those people with disabilities who enter the work force, especially those at lower income levels. Disability income systems in Canada have begun to move in this direction, but too tentatively to achieve significant results as yet. Of course, barrier removal and individual accommodation must be effectively in place for this to succeed.

Another "lesson learned" is that rehabilitation, training, education and return-to-work must be addressed *early* for those who are newly disabled. Reviews and evaluations of all disability income systems tend to focus on the significant problems created by long-term cases, which are expensive for the funder (government or insurer), and which almost invariably reflect a very difficult living situation for the individual. This point, also elaborated on elsewhere in this study, is closely linked to the previously-discussed issue of "unemployability". Too often, the newly-disabled person has limited resources, and little practical option except to apply for disability income as "unemployable". Then, two or three years later, rehabilitation or re-employment may be addressed, but in many cases, too late to be effective (although the CPP Vocational Rehabilitation Project and many other studies have shown that even those out of the workforce for several years *can* benefit from effective rehabilitation). The person has already long identified himself or herself as unable to work, and many others have made the same identification. Together with a more flexible approach to defining eligibility, disability income systems need to emphasize a much more timely approach to rehabilitation, including training, education and return to work.

Unlike other discussions of the "welfare trap" or "work disincentives", this study has *not* emphasized the details of how much employment income reduces disability income (the "tax-back"). There is little evidence to suggest that individuals with disabilities do a detailed month-by-month calculation to compare working with not working. As already indicated, their primary concern relates to the potential long-term or permanent loss of categorical eligibility. In any event, most experts have recognized that, in a disability income system, combining a fair

guaranteed level of security for all with a low "tax-back" for those who are working is unaffordable - unless rules are added which make persons who are working categorically ineligible over a certain income level. (Richard Shillington, Centre for International Statistics, 1994, costed a Guaranteed Annual Income with reference to the impact on persons with disabilities.) This may be an argument for a long-term policy direction towards separating out programs for those with disabilities who are working from programs designed for those who are not.

In summary, while there are many reports and evaluations concluding that opportunity and security should be balanced fairly in disability income programs, much work remains to be done on how exactly to achieve this.

C. The (Realistic) Prospects for Comprehensive Disability Income System Reform

A number of reviews and studies of various aspects of the disability income system in Canada have proposed that a comprehensive disability income system replace the current configuration of systems and programs (Weiler, 1983; Social Assistance Review Committee, 1988). But these proposals have typically been based on a few broad conceptual points rather than any detailed consideration of what would be involved in such a reform.

Advocates of "one big system" typically argue that it would be administratively more efficient, as many programs would be combined into one. They also argue that it would be fairer and more equitable, as the income and other supports received would no longer depend on factors such as the cause of an individual's disability.

There is some basis for both of these major points, but they are by no means as self-evident as their proponents might believe. With respect to administrative savings, it is common wisdom that larger bureaucracies are not necessarily more efficient. Nor do they necessarily provide better service. The equity issue is more complex. Different kinds of equities are involved.

Of the existing plans, some are for workers and contributors - workers' compensation, CPP/QPP, long-term disability. Other systems, such as no-fault motor vehicle accident benefits and court awards for personal injury, compensate earners on a higher level than non-earners. It is difficult to envisage a reform with no place for earners to insure their earnings, at least partially. Indeed, leading advocates of "universal" disability insurance schemes, such as Terence Ison (Ison, 1994), actually advocate a "universal" plan for *earners* and *contributors*, with a social assistance type of system for other persons with disabilities.

There are also equities related to justice claims. These are raised most forcefully by defenders of the personal injury tort system, who argue (as noted above) that those whose disabilities are caused by others have a right to full compensation by the party at fault. Justice claims are also at the basis of criminal injuries compensation. A somewhat different type of entitlement based on social justice underlies the veterans' benefits system. Injured workers and their advocates

advance a justice claim based on the historic "tradeoff" whereby the WC payment system was created at the cost of giving up the right to sue one's employer.

These brief indications are enough to show that there is by no means unanimous support for a "universal" disability compensation system, nor even a consensus about what such a system might involve or how it might work.

There are huge administrative and practical barriers to "putting together the systems" as well. The seven disability income systems we have discussed - and more would have to be included in a truly comprehensive reform - differ greatly. Some are in federal jurisdiction, some in provincial, and others, such as CPP/QPP, are effectively "mixed". Some are funded out of general revenues, some are funded through payroll deductions, and others are private. They all differ greatly as to benefit structure, administration, eligibility definitions, rehabilitation, and so on. It would be a monumental task to combine all of these in "one big system", even if a strong consensus that it should be done could be achieved.

For this reason, those who have sought to look at comprehensive disability income system reform in Canada have quickly moved from "one big system" to a consideration of intermediate steps that might be taken towards a more coordinated system.

The Joint Federal-Provincial Task Force established by federal and provincial Social Service Ministers in 1982 is the most significant attempt to realistically address the difficult issues involved in this area in Canada. The Task Force concluded (Health and Welfare Canada, 1983) that it would not be a realistic objective to combine all existing programs. Rather it put forward an analysis of six disability income program models, three for earners and three for non-earners. These models would build on existing systems but, in some cases, were quite different from them.

The models put forward by the Task Force for earners were:

- Mandatory Long-Term Disability Insurance;
- High Benefit Level CPP/QPP-Type Disability Protection Program;
- Expanded Workers' Compensation;

and for non-earners:

- Improved social assistance by a "special benefit" or "disability amount";
- Added flat-rate benefits for spouses and dependants;
- Old Age Security-based model.

No definite conclusions were reached as to the best approach, but these models serve to illustrate some directions that might be taken.

Other ideas regarding comprehensive reform in Canada are found in Beatty, 1991, 1992; Bolduc, 1992; Ison, 1994; Muszynski, 1992, Veil Squire, 1994. The Roeher Institute (1994a)

has developed a model for a comprehensive plan to meet the *costs* of disability, separately from income replacement.

D. Five International Comparative Studies

i. "International Comparison of Public Disability Insurance"

> A Working Paper for the CPP Disability Program Evaluation, Evaluation and Data Development, Strategic Policy, Human Resources Development Canada. March 1996. (SPR Associates, 1996)

This study compares the CPP disability program with QPP and with public disability insurance programs in seven other countries: Australia, Germany, Great Britain, the Netherlands, New Zealand, Sweden and the United States. Extensive comparative information was developed by the evaluation team.

Rapidly increasing caseloads are described as a "worldwide phenomenon". Although CPP had a period of exceptionally high increase, especially during 1990-95, the CPP still wound up with a *lower* percentage of people between ages 20 and 64 receiving disability benefits than any of the other countries. But is this a meaningful comparison? Probably not, as the entire *range* of disability income programs in a country would have to be looked at to decide whose program was "bigger".

It is an open question whether a period of significant increase in the caseload shows a problem with the program or not. As the population ages, as more disabilities become recognized and as jobs become scarce, one would expect a significant caseload increase. It may not be inappropriate at all.

Contribution rates are also very low in Canada, although again it is difficult to make true comparisons because the basic models from country to country are so different. Some (like Canada) have separate programs for contributors (workers) and others — basically a pension for workers and means-tested social assistance for others. Other countries have more of a "unified" model — essentially a universal program in Sweden and a generous means-tested one in Australia and New Zealand. Then there are very different approaches to the interaction between income programs, disability-related costs programs and disability-related services. It is difficult even to compare *descriptions* of the programs, let alone effectiveness.

Definitions of disability for eligibility purposes may be classed according to their dependence on *medical*, *functional*, or *vocational* criteria or factors. These may be used alone or in combination. The Quebec Pension Plan uses strictly medical criteria, which leads to a narrow definition. Great Britain has recently adopted a system based solely on functional criteria. The Netherlands has recently eliminated vocational criteria as well. This represents a significant narrowing of their previously very wide definition which brought in socio-economic as well as vocational factors.

Canada, like the United States, uses a combination of medical and vocational criteria. While there are a number of approaches, it is difficult to compare and determine which is the most appropriate. There is little doubt that a vocational test, even a strict one like "permanently unemployable" - basically the CPP test - is most capable of interpretation to include people whose disability is "enhanced" by the interaction with factors such as age, lack of education, and lack of experience at anything except demanding physical work. Jurisdictions seeking to narrow their criteria are, by and large, eliminating vocational factors. An important question is whether it is "right" or fair to do so.

Some of the countries in the study include partial disability in their national pension or income plan (Sweden, the Netherlands) or in a separate program (Australia, Germany), while Canada (like Quebec, Great Britain, New Zealand and the United States) does not. Partial disability is basically covered in Canada only in workers' compensation and motor vehicle no-fault schemes. But the implications of covering partial disability are unclear — does it mean benefits for those who otherwise would get nothing, or simply reduced benefits for those who otherwise would get full payments? Everything depends on how the program is interpreted — there is no consistent basis on which to make a comparison.

Benefit structures vary widely -- flat-rate, earnings related, needs-tested, dependent on family unit, and so forth — so again, comparisons are difficult. It appears clear, however, that CPP benefits are significantly lower than those in Sweden and the Netherlands, and the CPP *maximums* are well below Germany and the United States (but these countries have no minimums). CPP payments are more comparable to the regimes in Australia and New Zealand. The CPP *maximum* pension is less than $10,000/year and is only 31 per cent of Canada's average industrial wage - hardly the "gravy train" sometimes portrayed in the media. But there is no clear way of defining what level of benefit is appropriate.

CPP is not linked administratively, and poorly linked in practice, to short-term sickness benefits under Employment Insurance. This is largely because the EI sickness benefit program is so short - 15 weeks compared to what appears to be the international norm of one year. This study identified the transition from EI sickness benefits to CPP as one where improvements should be made so that persons with disabilities don't have an unfair interruption in financial support. (There are other reasons for looking at "the first year" as a key area for improvement. This point will be returned to in discussing the United States General Accounting Office report "Return-to-Work Strategies From Other Systems May Improve Federal Programs".)

In comparison with other jurisdictions, including Quebec, the study criticizes CPP for its lack of disability assessment guidelines, for having too centralized a process, and for failing to make effective use of the "team" (that is, "multidisciplinary") concept in assessment. As well, the onus is placed on the applicant to obtain and submit the necessary information, which may be an unfair burden for some, such as those with limited literacy skills. These appear to be legitimate criticisms. Clearly, a disability income program is failing to meet a key objective if there is no guarantee in practice that "like cases will be treated alike".

All of the jurisdictions under study have some sort of appeal system, but some (Australia, Germany, the Netherlands, and the U.S.) have an administrative, internal review process, while others (Sweden, Great Britain, New Zealand) have an immediate appeal to an independent tribunal. Canada's is something of a hybrid system. But the differences between the systems may be more apparent than real, as those countries that do not have an administrative review have or are developing more stringent standards for initial case development, which amounts to the same thing in practice. The evaluators favour devoting resources to the initial decision-making level, which is probably fairer to more applicants. But there is no real way of comparing systems against an "absolute" standard of effective and fair decision-making.

Finally, some countries - especially Germany, Sweden and the Netherlands - clearly place much more emphasis on rehabilitation and work incentives than does the CPP. The evaluation indicated, however, that there are fundamental features of their programs which make it easier to incorporate rehabilitation and work incentive initiatives, particularly the higher levels of disability benefits and the recognition of partial disabilities. There are, however, opportunities to improve CPP's record in this area, which have just begun with the National Vocational Rehabilitation Project - which was, however, very small in scope.

The overall impression left by the evaluation is that while CPP could benefit from ideas developed in other jurisdictions, it is not fundamentally flawed in comparison with the systems of other countries, nor is it fundamentally different from them in the challenges it faces.

ii. "Return-to-Work Strategies From Other Systems May Improve Federal Programs"

> United States General Accounting Office, Report to the Chairman, Special Committee on Aging, U.S. Senate, SSA DISABILITY. July 1996. (GAO, 1996i)

The GAO has prepared several recent reports on the United States Social Security Administration (SSA) and its Disability Insurance (DI) and Supplemental Security Income (SSI) programs. DI is the pension program for contributors (workers) while SSI is the needs-tested program for non-workers. A major focus of these critical reports is the general failure of rehabilitation and return-to-work. Less than half of 1 per cent of DI recipients ever return to work even though they all have a work history - an observation that can essentially also be made about Canada's CPP disability pension program, although the CPP record is somewhat better.

The GAO correctly emphasizes that rehabilitation and work incentive efforts can show big "dividends" even if there is only a little bit of success. For example:

> "SSA estimates that lifetime cash benefit payments are reduced by about $60,000 when a DI beneficiary leaves the rolls by returning to work and by about $30,000 when an SSI disability beneficiary leaves the rolls by returning to work."

and

> "For example, if an additional 1 per cent of the 6.3 million beneficiaries were to leave SSA's disability rolls by returning to work, lifetime cash benefits would be reduced by an estimated $2.9 billion."

It is *essential* to keep emphasizing that apparently very small, marginal gains in this area can have a very significant long-term effect on the costs of a disability income program. It is *not* necessary to have immediate spectacular successes.

The GAO evaluators suggest that the SSA should adopt the "best practices" of the social insurance programs in Germany and Sweden and of private employers in the United States. These systems are seen as effective in returning persons with disabilities to the workplace. The three leading strategies of these systems are:

- Intervene as soon as possible after an actual or potentially disabling event to promote and facilitate return to work.
- Identify and provide necessary return-to-work assistance and manage cases to achieve return-to-work goals.
- Structure cash and medical benefits to encourage people with disabilities to return to work.

These strategies ideally should be integrated into a comprehensive return-to-work program.

In the United States (and in Canada), however, there is a period of delay following the onset of a disability or major illness.

Instead of an early intervention to facilitate return-to-work, the U.S. and Canadian systems are focussed on long-term eligibility to receive cash benefits. As was seen in connection with the comparative study done for CPP, this leaves the disabled individual in the position of having to document an inability to work to avoid the risk of losing everything. The result is that the critical period for rehabilitation and return-to-work initiatives is wasted. Even though efforts may be made "down the road" to reintegrate the individual into the workplace, they are much less likely to be successful.

The U.S. and Canadian systems are similarly much too slow to provide effective rehabilitation services, including case management. By the time rehabilitation issues are considered, the individual may have lost confidence that there is a job to go to, and in his or her own ability to do that job. Individual planning for return-to-work needs to begin much sooner.

Finally, the U.S. and Canadian systems incorporate a number of disincentives with respect to return to work. In the United States especially, short-term cash benefits are high, and medicare eligibility is linked to remaining on benefits. There is little incentive for the disabled individual to return to the workforce in the short-term especially.

This evaluation, like the previous one, suggests much more attention to the initial period of disability when the crucial decisions are made. Too often, people who still should have a reasonable prospect of returning to work are forced after four months to document a total "inability" to work, so they can qualify for CPP (or LTD). Little if any support is given to the individual to remain in the workplace. More people would get back into the workforce if they were not forced to make the "in-or-out" decision so soon. Our system would serve people better in the long run if there were less emphasis on high benefits in the short term and more emphasis on an *effective* rehabilitation strategy, which allowed people to attempt return to work on an essentially "no risk" basis. And, if more people were returned to the competitive work force in this way, resources would be available to provide more adequately for those who have challenging long-term needs, and who are served most poorly by the current system.

iii. Annual Report 1994-95

Department of Social Security, Australia. (Department of Social Security, (1995)

What is most noteworthy about this Annual Report is not the specific content (although some of the most important developments in Australia are interesting in themselves), but the manner in which it is organized. The Annual Report is related to objectives that have been set out for the Department by Parliament. Each program, and the developments with respect to it during the year in question, is related to specific objectives set out for the program. As the introductory comments state: "The report is designed to allow an evaluation to be made of the Department's performance during 1994-95, particularly in service delivery and accountability, without reference to other sources." While this may be over-stated, the fact that the attempt is made makes the Annual Report extremely useful and informative.

A chapter in the Report, "Income Security for People with Disabilities and the Sick", covers seven programs: Disability Support Pension; Wife Pension; Carer Pension; Sickness Allowance; Mobility Allowance; Child Disability Allowance; and Postal Concessions for the Blind." Each program has its own identified Strategies and Performance Outcome Objectives.

For example, the Disability Support Pension has as a key strategy "linking of the income support aspects of this Program with employment, education, training and rehabilitation activities to facilitate customers' participation in mainstream social and economic life". According to the Report: "While numbers participating in Disability Reform Package assistance are still modest, some 6,500 returned to work from disability payments in 1994-95, an increase of 70 per cent on the previous year." As noted in our discussion of the GAO study, even this level of success can be significant.

But the objectives of the Disability Support Pension are not limited to "getting people off the rolls". They include: Resource Utilization, Evaluation, Adequacy, Self-Help and Financial Independence; Take-up; Administrative Efficiency and Customer Service; Protection of Customers' Rights, and Control of Incorrect Payment and Fraud. Taken together, this range of

objectives provides a more complete overview of a disability income program than would a narrow focus on caseload size and growth or on costs.

In the Australian system, caregivers are eligible for a separate "carer's pension". While the details are not all available in the Annual Report, it appears that this program is being upgraded as part of a community living strategy, and that the improvements are being "paid for" in part by phasing out the "wife pension", a categorical eligibility program for female spouses. In view of the important role played by "informal" caregivers and the high costs of institutional and residential alternatives to home care, a "carer" pension is something that might usefully be considered in Canada.

Mobility Allowance is another interesting Australian concept — it is lump-sum direct funding to those who need transportation support. The allowance appears to be at a standard level for those who are eligible, expressed in the report as $52.40 (Australian)/fortnight and indexed to inflation. Interestingly, in the whole country during 1994-95, there were only 54 requests for review presented to Authorised Review Officers, 12 appeals to the Social Security Appeals Tribunal, and 3 appeals to the Administrative Appeals Tribunal. This may reflect a high quality and credibility of initial decision-making or a perception that there is little chance of succeeding on an appeal (or both). What we do not know is whether there are alternative informal appeal routes, for example, through an MP's office.

The Child Disability Allowance, for parents looking after children with disabilities at home, appears to be more significant in scale than comparable programs in Canada. The total payments increased in 1994-95 by 10 per cent to over 87,000 children and a total expenditure of $188 million (Australian). It appears from these figures that the program is not limited to children with *severe* disabilities (as is usual in Canada) and that the *average* entitlement is more than $2,000/year (Australian). Health Care Cards are provided as well. The program appears to recognize to some extent the lost income due to a parent's inability (almost invariably the mother's) to work outside the home. The government in its Annual Report indicates that it is moving towards the use of "child disability tables" measuring functional limitations against an age-appropriate standard. It is not stated whether cost control is a motivation for this change but it seems likely in the circumstances that it is.

iv. "Social Insurance, Disability and Personal Injury: A Retrospective View"

John F. Keeler (Law School, University of Adelaide). University of Toronto Law Journal, 44, 275. 1994 (Keeler, 1994)

Professor Keeler reviews developments in Australia, New Zealand, Canada, the United States, and Great Britain over the past 25 years. He notes that, while there has been great interest shown in moving in the "no-fault" direction over that period, particularly due to the influence of Professor Terence Ison's seminal work *The Forensic Lottery*, only New Zealand attempted a truly comprehensive reform. Even then, New Zealand's scheme dealt only with accidents, not with all causes of disability, and its plan has been significantly cut back in recent years.

The value of Professor Keeler's paper is that it reviews in detail the legal debate about "no-fault" over the past 25 years, providing an assessment of the main arguments. But he also identifies a separate type of analysis of disability compensation programs, which looks at their social insurance and social policy aspects, and which is generally ignored in legal approaches to the problem. However, he cites Patrick Atiyah (Atiyah, 1993) in England and Stephen Sugarman (Sugarman, 1989) in the United States as significant exceptions - legal experts who know and discuss the social policy implications of disability compensation proposals as well.

Keeler discusses at some length the range of design and policy features that would have to be considered in a "universal" or "comprehensive" plan:

- Coverage - accidents only, or also injury and sickness?
- Should there be death benefits, too?
- Should disabilities ever be excluded because of conduct: criminal? self-inflicted harm? recklessness?
- Should there be a flat-rate minimum?
- Should there be provision for partial disability?
- Should there be an "earnings-loss" basis for compensation?
- Are there "minor" disabilities which should be excluded?
- What about medical, rehabilitation and long-term care benefits?
- Should there be provision for non-economic loss (pain and suffering, nervous shock)?
- How should the plan be funded?

and many other issues. This paper is a valuable overview of what is involved in carrying out an actual thoroughgoing reform of disability income systems.

v. *Disability, Work and Cash Benefits* (Edited by Mashaw, Reno, Burkhauser, and Berkowitz, 1996)[2]

This important recent publication from the United States contains a series of studies relating to the increase in recent years in disability program claims and to the prospects for return to work for persons with disabilities.

In their overview, Jerry Mashaw and Virginia Reno draw the following main conclusions (at pp. 27-29):

- The recent rapid growth in disability benefit claims is to a large extent a temporary phenomenon, created by the economic downturn of the early 1990s, the aging of the

(working-age) population, and the expansion of the working population due to women entering the workforce in increasing numbers.

- Private sector providers should be involved in rehabilitation in innovative ways.
- There should be a wage subsidy program for persons with disabilities (to supplement the American barrier-removal initiatives under the Americans with Disabilities Act).
- The effectiveness of both return to work initiatives and fairness of claims medical reviews could be improved by a better disability management approach.

E. Summary: Major Findings and Lessons Learned

- There is potential for a significant proportion of CPP beneficiaries to return to work with appropriate vocational rehabilitation services. Early intervention has been identified in other systems as a critical factor associated with successful return to work - but may require coordination with provincial governments, insurers, employers, and so forth.

- Even very small, limited successes in enabling a small proportion of claimants to return to work can result in very significant long-term cost savings. It is *not* necessary to have immediate spectacular successes.

- The all-or-nothing definition of "employability" used in CPP and other income security programs creates a powerful disincentive to rehabilitation and employment, and results in what has been termed the "welfare trap."

- Many people with disabilities are capable of some degree of work, but still would require income support. The all-or-nothing approach makes this problematic, to the disadvantage of both individuals and lack of potential cost savings to the taxpayer.

- There are no clear answers as to how best balance opportunity and security. A starting point may be to concentrate on recognizing the ongoing disadvantage of those who have disabilities but who nevertheless are working.

- The complexity of the income security system, or systems, as they affect people with disabilities in Canada, which results in inconsistencies and overlapping jurisdictions, has been well documented. A starting point for any reform would be a centralized information data base, so that at least the facts about all of the programs would be known.

- There are potential pros and cons to a comprehensive disability income system. There are high administrative and practical barriers. There is no evidence that a unified system will be more effective than the present situation. It could present new problems, as existing schemes are set up to address specific needs which could be lost in a one-size-fits-all approach.

- Alternatives that have been suggested include consideration of intermediate steps that might be taken towards a more coordinated approach.

- CPP could benefit from ideas developed in other countries. Nevertheless, it is not fundamentally flawed in comparison with other systems, nor is it fundamentally different from them in the challenges it faces.

6. Independent Living and Community Support Services

by Patti Bregman

A. Introduction

As we discussed earlier, there is evidence indicating that with the availability of appropriate services and supports, people with disabilities can be capable of employment. Services and supports can also enable people with disabilities to take part in a wide range of community-based services, on the same basis as others. A variety of services, however, may be needed to make this possible. This chapter discusses some of the relevant evidence, and indicates what is known about which types of approaches appear to be most effective.

As this chapter indicates, personal supports and community-based services are critical to the ability of people with disabilities to live independently and to participate in the community. They are essential to the citizenship and equality of people with disabilities. They are essential to employment. Numerous studies and reviews, including various parliamentary committees and most recently the Federal Task Force on Disability Issues (1996), have spoken of this.

Thus personal supports and community-based services can contribute to federal government objectives. Nevertheless, direct responsibility for these services is primarily under the control of the provinces and territories. It should be noted, however, that significant federal funding goes towards these services, through the Canada Health and Social Transfer, VRDP, the *Canada Health Act*, and through other vehicles. Some services may also be directly funded by the federal government. There are various mechanisms by which the federal government, if it wishes, could support activities in this area.

i. Types of Services

The two types of services most often associated with support or community services for people with disabilities are:

- attendant care (often referred to in the United States as personal assistance services — PAS);
- the more traditional home care services, which include professional services such as nursing and non-professional services such as homemaking assistance.

There are many ways in which these two categories of service can overlap. But they have been based on philosophically different models. Attendant care services are closely related to the independent living movement. The goal of most attendant care programs is to enhance independence and autonomy. The concept of self-direction is central to the delivery of attendant care services.

In contrast, community or home care services have traditionally been seen as part of the more professional or medical approach to the care of people with disabilities. However, there may now be a coming together of the two models. In some jurisdictions, home care programs are now beginning to adopt the philosophy of independent living.

Attendant Care Services: A General Description

Attendant care services provide to people with disabilities assistance with activities of daily living. This can include, but is not limited to, assistance with bathing, dressing, and eating, as well as with work-related activities. Attendant services may be provided in a variety of different settings and by different types of service providers. For example, services may be provided as:

- Outreach attendant care

  These services are provided through an agency to persons with a disability in their homes, workplaces or other settings. A set number of hours and services is contracted for. Services are not available 24 hour a day.

- Support Service Living Units, or similar congregate living settings

  In this type of arrangement, a cluster of apartments enables attendant care services to be provided to a group of people with disabilities in their homes. Specific hours of service are contracted for, but attendants are present on site 24 hours a day and are available on an emergency basis. Services are provided only in the home setting, not in school or at a workplace.

- Direct Funded Services

  A program that provides individuals with the funds necessary to purchase their own attendant care services is growing as an option in many jurisdictions. Alberta, Manitoba, Ontario and Quebec have direct-funding projects. Attendant care services in the United States are also provided to people through the Medicaid System on a direct funding basis. Increasing attention is being paid to the direct funding approach. Later in this chapter, we discuss findings from evaluations of various direct funding models.

Home and Community-Based Services

Home and community-based programs serve a wide variety of needs, ranging from home nursing services to support for individuals with disabilities in the workplace. In some cases, they can include attendant care services. These programs are receiving increasing attention for a variety of reasons (see Nosek, 1991; Spillman and Kemper, 1992):

- to enable people who are being released from institutions to live in the community;

- as a result of demographic pressures, resulting in an increasingly aging population who will need more services in order to be able to remain in the community, with the alternative being costly and undesirable institutionalization;

- a means of providing essential services to people with acute or chronic illnesses who would otherwise have to be hospitalized.

ii. Other Characteristics of Community Support Services

These services can vary across a number of different dimensions, such as:

- Purpose of the service: does it support employment, recreation, health, education, social activity or a combination?

- Population served: are they seniors, people with mobility disabilities, people with intellectual disabilities?

- Location of delivery: community-based or operated out of an institutional setting;

- Type of provider: services provided by family and other informal caregivers, professionals, paraprofessionals;

- Direct or indirect service: services providing care or services directly to individuals, or services directed at improving the quality of care offered by agencies;

- Funding source: federal government, provincial government, private payment, or insurance.

B. Policy Direction for Services and Implications for Evaluation

As Chapter 1 indicated, there have been important policy evolutions in recent years with respect to how people with disabilities are viewed. Canada, along with most other western governments (Lunt and Thornton, 1993) has moved from a philosophy of paternalism to one which encourages and respects independence and responsibility. The Mainstream 1992 Review (Mainstream, 1993) indicates the evolution from a "warehouse" to "greenhouse" to an "open house" vision. This "open house" vision has been endorsed by all federal, provincial and territorial social service ministers, as well as by the federal Standing Committee on Human Rights and the Status of Disabled Persons.

This shift in vision has particular implications for the manner in which community-based services are provided, and for how they need to be evaluated. This evolutionary shift, with its major implications for community-based services, is discussed briefly below.

Stage 1: Deinstitutionalisation (Warehouse Model)

The institutional approach was based on an assumption that people with disabilities, for the most part, are permanently incapacitated and therefore deemed to be incompetent. This approach focused on the care and protection of people with disabilities, primarily in institutional settings.

Over the last 20 years in particular, community living has replaced the institution as the model of choice for delivering services to support people with disabilities. Early evaluations demonstrated that people with disabilities could live in the community. A wide range of research studies identified the types of services needed and looked at different delivery models for the services. (For a review of evaluations of early programs analysing home care services in the United States, the United Kingdom, Canada, the Netherlands, Sweden, France and Italy see Lesemann and Martin, 1993; also see Weissert, Cready, and Pawelak, 1988; and Lord, Hutchison, and Farlow, 1988).

These and many other studies have documented the benefits of community-based services for a number of reasons, including the ability to live and to become part of the community as well as increased abilities in self care (Boschen, 1995; Lakin, Blake, and Prouty, 1991; and O'Brien, 1996). Evaluation approaches are now examining the factors associated with successful transitions from institutional to community settings (Lemieux-Brassard, 1995). Evaluations in progress are examining deinstitutionalisation in a number of provinces, including Saskatchewan, Prince Edward Island, Newfoundland, Ontario, Manitoba and Alberta. Problems in deinstitutionalisation arise when the necessary community services are not available.

The seminal Pennhurst Longitudinal Study (Conroy and Bradley, 1985) of a court-ordered deinstitutionalisation of the Pennhurst State School and Hospital in Pennsylvania, tracked residents over five years after they moved to community settings, and documented many benefits. This study, in common with others, documented changes in attitudes of families towards community placements. Initially, family members were concerned about the possible impact on their relatives, with 55 per cent strongly opposed. But after community placements, opposition dropped to 4 per cent. Conversely, before placement, only 19 per cent agreed strongly, whereas this increased to 66 per cent afterwards.

Stage 2: Acceptance of Community-based Services (Greenhouse Model)

More recently, the use of community-based services has become the preferred model, leading to the closure of institutions. The "greenhouse" approach recognizes the capacity of individuals. It has a strong focus on rehabilitation, on supporting individuals in caring for themselves and adapting to the existing environment. This change in countries around the world has been well documented (GAO, 1994d; Mainstream, 1993). The GAO study identified the need for long-term care services and explored how various countries are dealing with this and the increasing cost.

Stage 3: Independent Living Principles (Open House Model)

The "open house" vision, as expressed by the Mainstream review, "reflects a society which is accommodating to its citizens with disabilities, which understands the importance of empowerment of people, which recognizes the necessity of adapting the social and physical environments, and which acknowledges the rights and responsibilities of people with disabilities." An important development, consistent with the open house vision, is the growth of the independent living movement (which as Boschen, 1995 indicates, emerged some 20 years ago, but has become more widely accepted over the last few years).

Independent living has been defined by the Canadian Association of Independent Living Centres as "a process whereby disabled citizens achieve their desired individual lifestyles by assuming responsibility for the development and management of personal and community resources." Key principles of an independent living philosophy include autonomy and control by an individual over her or his own services. This differs from the traditional model where these decisions tend to be made by professionals.

The role of the disability movement in articulating and establishing the independent living philosophy as the core of personal support services is well documented in a recent evaluation of the Independent Living Resource Centres in Canada (Hutchison, Dunn, Lord and Pedlar, 1996).

Independent living has been valued for its own inherent recognition of the autonomy and independence of people with disabilities. A review of programs, policies and legislation in many different jurisdictions suggests that independent living principles are now broadly accepted and incorporated into programs providing personal support services. It is being incorporated into the legislation in a number of different countries - the Rehabilitation Act in the United States, the Disability Services Act in Australia, and recent legislation in the United Kingdom for example.

There is, however, some evidence that a fundamental shift from a medical model which encourages dependence to one based on independent living principles may exist more in name than in practice. This is discussed later in this chapter.

Implications for the Focus of Evaluation of Community-Based Services

Thus there is no longer any question about whether or not people with disabilities can live in the community. More recently, there has been acceptance of the principles of independent living for community-based services. The focus of evaluation accordingly has shifted to addressing questions such as: to what extent are programs and services consistent with these principles and how effective are these services at improving the quality of life of individuals? Evaluation is also exploring the appropriateness of various service models, and in particular, which approaches are most effective at addressing the needs of specific populations or in different settings.

Many of the personal support services based on a philosophy of independent living have historically served people with particular types of disabilities or needs, such as people with spinal cord injuries. The early programs required persons with a disability to be able to direct their own services and to live independently in the community thereby limiting the services to people with a minimum level of intellectual capacity and experience.

In recent years, services based on the independent living philosophy have been expanded to serve other population groups, such as people with intellectual disabilities. The focus of evaluation and research has been shifting to examining the best means of delivery to different client groups. Evaluation is also examining the impact of external factors, such as living conditions and locale, and implications for program design. Both the National Institute for Disability Research in the United States and the National Health Service in the United Kingdom have major research funding programs underway looking at a range of different types of programs to evaluate their effectiveness and how they can be improved. These research studies are also examining ways of serving people with varying needs, such as people who are deaf or hard of hearing, people with brain injuries, visible minorities, people with psychiatric disabilities, and people with developmental disabilities.

As discussed in more detail in Chapter 7, there is also increasing recognition that evaluation needs to focus less on the quality of the service being delivered, and more on the impact of service on the overall quality of life of the persons receiving the service. For example, the outcome-oriented evaluation process developed by the Accreditation Council (1993) for community agencies is based on this philosophy.

The variety of service types and models of delivery reflects the diversity of needs in the community and makes the creation of "the ideal" program impossible. This does not mean that evaluation research is not relevant or necessary. New and more responsive services and methods of service delivery have evolved over the years in response to individual needs, government budgets, and changes in the underlying philosophy from a system in which the medical model prevailed to one in which autonomy and independence are seen as central.

C. Impact and Effectiveness of Alternative Approaches to Independent Living

Some Overall Findings

Following are some overall findings emerging from the literature on the overall impact of independent living, as well as its contribution of related factors.

Acknowledging and Responding to Differences

Personal support services can involve every aspect of a person's life. For many people with disabilities, the attendant or service provider enables them to get out of bed in the morning, get dressed, eat and work or otherwise participate in their community. The attendant responds to the individual's need for physical assistance to carry out routine activities of daily living.

However, these needs are not the only barriers preventing people from fully participating in society. While support services play a significant role in enhancing the autonomy and independence of people with disabilities, there are also other factors that may impact and affect the success of the support service programs.

In addition, the differing goals and populations served by these programs make it impossible to identify one specific model that will work for all, or even to identify only one goal to use as the basis of evaluation. For example, some programs may be intended to assist people attending university, while others may assist people to live in the local community instead of an institution.

In a study funded by the National Welfare Grants Program, Kathryn Boschen (1995) examined personal support service delivery in Canada. This study identified a number of factors that lead to successful outcomes in terms of enhanced independence, participation in society and quality of life. These factors include: type of disability, psycho-social considerations, infrastructure of the programs including involvement of consumers in their operations, and environmental factors such as transportation and housing. The study also found that responsiveness of the program to individual needs was important.

The study indicated the need for a broad range of services which are sufficiently flexible to meet varying needs of individuals. It also identified the need for integrated education as well as vocational and life skills, financial support and access to transportation as well as housing and assistive devices. Advocacy was also identified as an important component. The study recommended the use of direct funding approaches, as well as peer counselling such as that provided by independent living centres, along with family and community supports strengthened through government and community agencies.

The study found that the more productive people tended to be more educated and have higher levels of functional ability, as well as an accessible home environment and transportation. It left open the question of whether increased productivity precedes the ability to make effective use of the services or whether it follows the other factors.

A United Kingdom study (Department of Health, UK, 1996) which explored factors contributing to the social isolation of people with arthritis also identified the importance of considering a range of factors. This study indicated that rural living, lack of access to transportation and inappropriate housing are major factors contributing to isolation. Poverty, lack of education and employment are also factors. In addition, this study identified, as did Boschen (1995), other factors contributing to isolation, including lack of information about available services, restrictions on the types of services available, inappropriate housing, lack of transportation, education, equipment and employment. The study also found that assistance in the support of self-advocacy was effective and enabled people to identify and to obtain the services to meet their needs.

A Dutch study (Kuyvenhoven, Marijke et al., 1996), looking at an innovative home care project for severely disabled elderly people with difficulties in carrying out many activities of daily

living, found that single people living alone had poorer health and a lower state of wellbeing than married people. The study indicated that there is a need for more architectural adaptations and personal attention by care providers for people living by themselves.

Respect For Individual Needs

A theme emerging from evaluations of many different types of programs is the importance of respect for individual needs and desires. For example, a recent Swedish study (Sjogren, 1996) led to the recommendation of a model for individualizing service delivery. The suggested process looks both at the individual's own objectives and how the person experiences his or her own situation. The goals of the process are also reflective of many studies: full participation and equality and a good quality of life for the individual and his or her family.

Value of Independent Living Principles

As noted above, the focus on independent living principles of autonomy and independence is not just a philosophical preference. Studies of various types of support services consistently identify a strong preference by clients for those services that enhance independence and autonomy (Lord, McGeown, Taylor, and Young, 1992; Marrone, Hoff and Helm; O'Brien, undated; Smith et al., 1993).

This applies not only to the actual support services provided to individuals, but also to the indirect services, such as peer counselling and training provided by agencies and consumer-run organizations such as Independent Living Centres. Consumer autonomy and control, as well as the responsiveness of programs to individual needs, is consistently ranked high in evaluations of support service programs. It is also used as the basis for evaluating these programs, such as Nosek's (1991) review of the literature of personal support services and in the evaluation of Independent Living Resource Centres in Canada (Hutchison et al., 1996).

Boschen's (1995) study also documented the importance of *control* to satisfaction and other measures of successful independent living. She found that those who ranked their lives as more independent had greater functional ability, access to affordable and accessible housing, support of family and friends, and a feeling of personal control over their lives. Locus of control was found to be more closely related to quality of life than other factors, such as the level of independent living or productivity.

D. Direct Funding

Direct funding (also often called "individualized funding", "service brokerage", or "self-managed attendant care") provides funding directly to the consumer to hire his or her own attendant or support staff. This contrasts with the typical model where funding is provided directly to an agency. Direct funding permits individual clients to hire and to direct their own

staff. Depending on the model, the consumer may be completely responsible for all financial aspects of their services including payroll duties. Staff hiring and training can also be part of the program.

The direct funding model puts control directly in the hands of the consumer, rather than the service provider. It enabled individuals to purchase their own services and to arrange them in a way that is most suitable to them. The service provider is dependent on the consumer for continued funding, rather than vice versa as with traditional funding models where agencies have control over which services will be provided and how. Direct funding is consistent with the independent living philosophy. It is also consistent with the general societal trend towards making public and private services more responsive and accountable to the end user.

Various models of direct funding are becoming increasingly common in Canada and in the United States. There is also interest elsewhere, such as in Australia, where the Law Reform Commission (Baume and Kay, 1996), in a recent evaluation of the *Disability Services Act* in that country, strongly recommended the incorporation of provisions for direct funding in the legislation.

There has been a significant amount of evaluation of direct funding approaches, in Canada and in the United States, demonstrating the effectiveness of the model. Other evaluation studies, exploring the model in more depth, are currently in process.

For example the Self Managed Care Pilot Project in Alberta (Alberta Health, 1993) was recently evaluated. The project had three goals:

- To provide home care clients with the opportunity to manage their own support services through funds received.

  The evaluation indicated that this goal was met, with nearly 70 per cent of the clients feeling comfortable about managing their own funds.

- To enable clients who select the self-managed project to increase control over their lives and enhance their personal dignity and well being.

  This occurred for all of the recipients. In addition both case managers and staff also believed that the goal was achieved.

- To demonstrate the effectiveness in both quality and cost of self managed care.

  Because of the short time frame, the evaluation was not able to make conclusions about cost effectiveness. However, it identified significant improvements in quality of life, along with improved health and social status and few risks or problems arising.

Indeed, the evaluation found that the greatest positive impact of the project was on the clients' sense of personal control. The program also had positive effects on families. As discussed

below, this is important, because the increased stability and financial situation provides for more positive interactions among family members.

A recent evaluation of a Quebec direct funding program (Tourigny et al., 1996) similarly found that the model had a number of strengths. These included the flexibility of being able to adapt services to individual needs, freedom to chose, and the ability to pay those providing the service (as opposed to being forced to rely on inconsistent help in some cases from volunteers or family members). Consistent with other studies of direct funding, this project documented enhanced feelings of dignity and self esteem.

The Roeher Institute (1991) evaluated a service brokerage and individualized funding approach in British Columbia for individuals with intellectual disabilities. This evaluation similarly found that the approach led to increased self determination, autonomy, and dignity. It provided greater flexibility to be able to respond to changing needs. A factor of particular importance was the contractual status provided to individuals, which they could use to negotiate agreements with service providers about the services they were to receive and under which conditions. The Roeher Institute (1993) has also issued a publication reviewing approaches to individualized funding in Canada.

An evaluation of Enable in the United States (O'Brien, undated) compared a variety of delivery methods including direct funding and agency provided services. The evaluation found that clients believed they had greater control over their lives, particularly the ability to choose their own attendants. Most indicated that they were able to receive the services they needed, although those with high needs did not think they received sufficient services or the proper services because of restrictions by Medicaid. Clients expressed dissatisfaction with traditional agency services where the person has no choice. They considered the quality of staff hired through direct funding to be higher than those provided by agencies.

There are also some evaluations under way. For example, the Roeher Institute, in conjunction with the Centre for Independent Living Toronto, is completing an evaluation of Ontario's direct funding and self-managed attendant services project. The study includes a comparative financial analysis of different systems of funding attendant services, including direct funding, outreach programs, and supported living arrangement.

Despite the overall success of the direct funding models, evaluations discussed above have identified a number of issues that still need to be resolved. Key issues include:

- Management of the administrative tasks: In some programs, the individual is responsible not only for hiring the employees, but for filing appropriate taxes and doing all bookkeeping. The Alberta study found that 54 per cent of clients needed some assistance from family, friends or agencies to assist with financial duties.

- Availability of alternatives: Choice can be more illusory than real if there is not a selection of service providers to choose from. This can be a particular problem in rural

areas. The Quebec evaluation indicated that a number of people had difficulty with recruitment.

- Ability and skills of clients to make hiring decisions and to provide ongoing direction: It is not clear whether some types of individuals may be better suited than others to benefit from direct funding.

With respect to the last point, it should be noted that one of the functions of independent living centres in the Canada and in the United States, as discussed below, is to provide training and assistance to clients to help them in carrying out their new duties.

E. Impact of Independent Living Centres

Independent living centres (ILCs) aim to enable participation and integration by empowering individual clients to take charge of their lives. Rather than provide technical aids or advocating on behalf of clients, ILCs encourage and enable clients to do this for themselves (Hutchison et al., 1996).

A recently released report, based on a two-year study of Independent Living Resource Centres in Canada (Hutchison et al., 1996) evaluated the impact of independent living resource centres on individuals with disabilities. The evaluation documented the efficacy of the independent living model, as expressed above. The evaluation indicated that ILCs had significantly assisted individual clients with their feelings of self esteem and assisted them in the development of useful skills which in turn led them to take charge of their own lives. This significantly assisted individual clients in improving their lives, sometimes dramatically so, and in participating in regular life in their communities. The evaluation also found evidence of growing acceptance of independent living principles and practices in the wider community.

The evaluation indicated that ILCs had more positive impacts on people's lives than rehabilitation and other formal services. It indicated that the individual empowerment model was particularly important in enabling people to become competent in a variety of community living skills.

Thus ILCs can provide the support necessary for an individual to be successful in making use of support service programs. A wide body of research from a variety of jurisdictions (Boschen, 1995; Dept. of Health, 1995; Hulgin, Shoultz, Walker and Drake; 1996) documents the importance of services such as peer counselling and advocacy in making support service programs, particularly those responsive to and accountable to the individual, effective. Learning how to direct services, finding and successfully obtaining services takes skills that people may not have when the need for the service first arises. Yet, without these skills, it is unrealistic to expect a person to be successful in independent living.

An evaluation of United States independent living centres administered under the *Rehabilitation Services Act* confirmed the importance of advocacy and skill development services. This evaluation identified a wide variety of services and advocacy available at the local level through programs that respond to and reflect individual and local needs. For example, programs worked on improving accessible transportation, improving access to buildings, educating the public about people with disabilities to break down barriers, and supporting employment opportunities.

In addition to providing funding for services to support independent living through various state initiatives, including independent living centres, Title V of the *Rehabilitation Act of 1973*, also provides for advocacy assistance for individuals who need services beyond the scope provided by other programs. This can provide for the protection of both legal and human rights of people with disabilities. Individual advocacy services include assisting with the enforcement of the *Americans with Disabilities Act*, the *Fair Housing Act* and other human rights legislation.

The availability of training also seems to improve the ability of people with developmental disabilities to live successfully in the community. A United States study (Lakin, Blake, Prouty et al., 1991) indicated that individuals who received a greater amount of independent living skills were more likely to continue living independently. The amount of training, however, did not seem to have an impact on the probability of improving or maintaining skills, suggesting an ongoing need for skills training.

Other settings, such as those which deliver health care services, have also recognized the importance of having independent supports available for people living in the community. These are necessary so that individuals can both obtain the necessary services and use them appropriately (GAO, 1996c).

F. The Role of the Family

Evaluation studies are documenting the role and impact of the family on the ability of people with disabilities to participate fully in society. The family can take on a number of different roles.

i. Family Caregivers

Despite the availability of government or privately-funded support services, families still provide the overwhelming majority of support services to people with disabilities regardless of their age. It is estimated that in Canada and the United States family members provide between 70 and 80 per cent of all personal support services (Metro Toronto District Health Council, 1995).

A number of societal changes are raising questions about whether families can and should continue to provide this level of support. Since most of this informal care is provided by women, the return of women to the workforce has had an impact on the availability of family

caregivers, particularly for seniors where the woman may have obligations to care for elderly parents and younger children (see Kemper, 1989; Lesemann and Martin, 1993; and Spillman and Kemper, 1992).

In addition, evaluations are indicating that the added stress of care giving may have a negative impact on the caregiver's own health and ability to cope. The growth in respite services is just one means of dealing with this reality and reducing the risk that caregivers will require health or social services themselves.

For example, one study ("Patterns of Caring for People with Dementia in Canada") compared the health of caregivers caring for people with dementia and the health of caregivers for people who are not demented. It found that 94 per cent of the caregivers for people with dementia are unpaid family members, relatives or friends. They rarely use community support services. Those caring for a person in the community are more likely to experience chronic health problems and depressive symptoms, to feel more burdened than those whose family member is in an institution.

It is interesting to note that the evaluation measures of a number of the projects reviewed (Silverman et al., 1995, for example) include the impact of the program on caregivers, family and other informal support. The types of programs considered range from independent living to geriatric assessment programs that enhance the rehabilitation of aging seniors.

ii. Family Support of Independence

Caregiving is not the only role that families play. Boschen's (1995) research, as well as other studies, show how the support of families may also play a role in successful independent living. It is therefore important to recognize that families, like service providers, may view the world differently than the consumer. A United Kingdom study (Heyman and Huckle, 1993) compared the attitudes of adults with intellectual disabilities and their carers towards dangers and risks they might face in the community. The researchers looked at a variety of topics including relationships with the opposite sex and independent living. It found that the category of risks and dangers was the most important aspect of independent living discussed. The areas of most concern were physical hazards, hazards from other community members, sexual hazards and hazards from other adults with learning disabilities. They found that family members had a different perspective towards the hazards than those of the adults with disabilities or their caregivers. In particular, professionals and people with manual skills seemed most concerned with hazards as dangers to be avoided.

Independent living centres and similar types of programs providing broad-based advocacy, training and education have been proven useful in providing the individual with support when making the transition from the family home to independent living in situations where the family may be apprehensive about the move. The programs give the individual the self-confidence and support to make the move successfully.

G. Impact of Other Factors

i. Housing and Living Arrangements

A number of studies have identified the importance of housing to the success of community-based programs. Issues related to housing involve affordability and accessibility. The relationship between environmental factors including access and independent living has been recognized early in the development of independent living (DeJong, 1981).

Both Canada and the United States have a housing crisis for people with disabilities who have low incomes. In the United States it is estimated that many people with disabilities are living in substandard housing, paying 50 to 75 per cent of their income on rent or else living at home with elderly parents, or are homeless. A report by Housing and Urban Development (1994) identified people with disabilities as the group most likely to live in severely inadequate housing.

Inappropriate housing was also identified as a barrier to participation in the community and a factor in increasing dependency rather than independence. One study (Sapey, 1995) looking at the housing needs of people with disabilities who use wheelchairs, indicated the importance, yet again, of involving clients in planning. This study found that when the people were not involved in the process of planning for housing, the final result was inappropriate housing and increasing dependency. Ratzka (1994) indicated that while renovating existing buildings to make them accessible can be costly, building the same structure with barrier-free design from the beginning requires only minor increases in construction costs.

At least one study (Kemper, 1989) has found that living and demand for care arrangements, including formal and informal care, are related and that changes in one will have an impact on the other. In addition, family availability and employment as well as income and price also determine whether paid or unpaid care is used.

ii. Effectiveness of Assessment Services

Support service programs depend on effective assessment of needs, not only for the services, but for the other components of a person's life such as housing and transportation. Traditionally, assessment programs revolve around professionals and ignore the input of people with disabilities and their families. One of the most attractive components of independent living programs is the degree of self-assessment it entails. Assessments not only involve the need for particular types and quantities of personal services, but also take into account environmental factors.

Evaluation studies have found mixed results in the effectiveness of assessment programs, whether done by the individual or professionals. This suggests that it is an area requiring further study. For example, the Alberta evaluation of the direct funding pilot (Alberta Health, 1993) found some variations in the actual hours and types of services used from those identified in the initial assessment. The effectiveness of self-assessment of barriers and needs seems to be more

problematic for people with disabilities who are elderly. The enhanced expertise of a geriatric assessment program was found to identify a higher level of cognitive impairments, depression and other functional problems than the community health program assessment, leading to an increase in satisfaction for the individual and less stress for the caregivers (Silverman et al., 1995).

One study indicated that expert assessment of barriers in the home setting which might impede independence could be useful (Steinfeld and Shea, 1993). This study found that the self-report did not always provide an accurate picture of the actual living situation. It also found that many of the needs were unique to the individual, requiring flexibility in the assessment.

iii. Services for Different Populations

As noted earlier, a number of research programs are underway looking at how support services based on the independent living principles can be adapted to serve a variety of specific populations. Because the fundamental principle of independent living is flexibility and responsiveness to the needs of the consumer, adaptation is possible in most cases. But while independent living principles can be widely used, there are a number of differences which must be taken into account when developing specific programs and services for individual populations.

There is an increasing number of research and evaluation programs focusing on services for special populations including people with intellectual disabilities, psychiatric disabilities, frail elderly and minorities. The results that are available suggest that:

- Specialized programs may be useful to deal with specific types of problems such as alcohol addiction, violent behaviour and language or culture issues.

- Programs should take special needs into account with respect to training, consumer education and methods of providing service.

In order to meet the unique needs of individuals, some variation will be required and special programs established to target particular needs (Boschen, 1995). While generic programs might be effective, some studies indicate that specialized programs will be even more effective. For example, a United Kingdom study looked at costs and qualities of four different models for 40 adults with multiple disabilities. The models were: institution-based units, campus-style further education service, community-based group homes and "ordinary" community-based group homes. The study found that on almost all measures of outcome, the specialized group-home model was the preferred model although it was not necessarily the highest cost.

Seniors

A great deal of interest is being shown in the use of community support services by seniors with disabilities. Seniors have the highest rate of disability in Canada. Research into the use of these

programs is resulting in the recognition that services such as attendant care services can benefit people with a broader range of disabilities including seniors with disabilities.

The rapid growth of interest in this area is evidenced by a recently published literature review which looked at publications between 1992 and 1995 relating to assisted living for the frail elderly, a fairly narrow topic. The review, part of a national study of assisting living in the United States which is currently in progress (Hawes, Manard, Kane and Molica, 1997) found 175 articles published between Jan 1992 and Sept. 1995.

The authors indicated that they were surprised to find little consideration in the published research of the potential of assisted living to decrease the use of institutional placing in higher care settings, such as nursing homes. The review did show that assisted living improved the quality of life to some extent. The authors suggest that further study is needed to find out why the substitution of assisted living for nursing homes is not occurring at the expected rate. There is a current study in the United States looking at assisted living to identify where it fits into the system and how it addresses the needs of seniors. Among the criteria to be evaluated is the extent to which assisted living embodies the principles of consumer choice and autonomy as well as affordability and its potential substitution for institutional care.

Findings from evaluation are also challenging assumptions that programs that promote autonomy are inappropriate or not wanted by seniors. For example, one study (Sheets, Wray and Torres-Gil, 1993) examined the differences between programs offered to people with disabilities under the *Rehabilitation Act of 1973* and programs funded through the *Older Americans Act* for seniors with disabilities in the United States. It found that programs for people with disabilities promote the enhancement of personal choice and support independence. The programs for the elderly disabled emphasize services that diminish personal autonomy and increase dependancy. The study suggested that advocacy efforts should focus on educating the professionals and clients of the value of geriatric rehabilitation.

This is consistent with other studies that show that consumer control for the elderly with disabilities is as important as for younger people. One of the studies done for the National Forum on Health reviewed the factors that resulted in seniors maintaining independence and identified programs it considered successful. Control was considered an important factor in leading to success.

iv. Cost Effectiveness and Decreased Institutionalization

The growing population of seniors and people with disabilities, as well as shrinking budgets for social and health care services in many jurisdictions has once again turned the attention of government and researchers to the cost effectiveness of programs. There are several studies comparing long-term care programs in different countries, considering both costs as well as strategies to deal with increasing costs (GAO, 1994c,d). These studies identify three trends in methods used in the countries studied to control costs and improve administration of services:

- Fixed budgets along with cost controls

- Consolidating delivery of long-term care through coordinated administration
- Increased public support for long-term care

While these trends are evident in long-term care services in Canada, as reflected in the increasing regionalization of health and long-term care services, it is too early to assess whether these changes have actually succeeded in reaching the goal while maintaining the level and quality of service. This is particularly true in the United States, which has seen a significant rise in the cost of long-term care services. Among the results expected were a decrease in hospitalization as well as overall reduction in costs.

One of the justifications for the expansion of home based programs was deinstitutionalisation and expected cost savings. There is some work suggesting that these goals have not been achieved. Research is currently underway to determine the extent to which it occurs. Some studies show that it does not necessarily decrease institutionalization, but researchers analysing those studies hypothesize that this may result from the fact that the programs may not be targeting those at highest risk of institutionalization. Results from a small project in Tennessee show that providing these services can be successful in moving people into the community who have been in an institution for a number of years.

Cost effectiveness in the United States is also used as the basis for determining whether a service is provided in an institution or at home. In reviewing these evaluations, a number of factors must be considered before making policy decisions based on the results.

Simply comparing costs of services does not reflect the true cost of a program. While delivering some services in an institutional setting may be less expensive, if the person receiving the service cannot participate in the community, obtain employment and generally have a higher quality of life, the actual financial as well as social cost may be higher. Again, there is a need for an understanding of the full costs of disability in order to be able to carry out effective cost analyses.

It is also important to identify the characteristics of those served by various programs. For example, community services programs may not be serving the same type of people as those being served in institutional settings. It is important to determine if this is in fact the case since it may help target assistance more appropriately where the goal is reduction of deinstitutionalisation.

H. Incorporation of the Principles of Independent Living into Agencies

Finally, as indicated at the beginning of this chapter, questions have been raised about the extent to which agencies in particular have actually incorporated the independent living principles into their day to day practice. Despite formal support for principles of independent living, some research suggests that organizational change is still a major challenge.

Principles of independent living are increasingly being incorporated into policies, programs and legislation. For example, in the United States Title VII, Ch. 1, Part B. of the *Rehabilitation Services Act* authorizes grants to assist states to promote the philosophy of independent living which includes consumer control, peer support, self-help, self-determination, and equal access to an individual system of advocacy to maximize leadership.

Similarly, in Australia and the United Kingdom, there is new legislation providing for the direct funding of services and expanding the role of community services. In Canada, all provinces have programs for attendant care services and other long-term care services in the community. Ontario, Manitoba and Alberta have established programs to provide direct funding to people with disabilities to enable them to purchase their own services without going through the more traditional agency. However, evaluations are raising questions as to whether these principles are in fact operational in a real sense, or in form only.

Two recent studies suggest that organizational change is still necessary to deliver services based on an independent living model, even in institutions which "nominally" adopt these principles.

A study done by Whitney-Thomas and Thomas for the Institute for Community Inclusion looked at the impact of the 1992 *Rehabilitation Act,* which established standards for rehabilitation practice, on the administrators and counsellors of those agencies. Both administrators and counsellors believed that some change had occurred, with administrators thinking more change had taken place. These changes occurred in the context of consumer empowerment and choice, assistive technology and accommodation, consumer involvement and services for people with HIV and AIDS. Neither of those groups believed any real change had occurred.

Hagner and Marrone (1995) also looked at this issue and found that fundamental agency changes have not yet occurred. It is apparent that while the language and philosophy of independent living is often used as the model for developing services, many agencies have not yet incorporated these principles and philosophy into the actual delivery of services.

The Roeher Institute (1992), in a study of personal supports in Ontario, identified a number of problems with how they are delivered. For example, they tend to be framed on a medical/rehabilitation model, rather than on principles of independent living. Clients have little control over how services are delivered, and few opportunities to making choices and provide direction for services. Personal supports also appear to be geared toward persons with ongoing stable conditions, and cannot respond well to individuals with high care needs.

The evaluation of ILCs in Canada (Hutchison et al., 1996) did not look specifically at consumer responses to community-based services and attendant care. But it did identify characteristics which people using those services find important. For example it indicated that clients valued being independent, being respected and considered part of the community. It also indicated that these factors are key to success in achieving community integration. This suggests that these characteristics would also be fundamental to the delivery of an effective community-based service.

In particular, it suggests characteristics for organizations that can improve their effectiveness in serving people with disabilities. For people with disabilities, the structure of service delivery may be as important as the actual service itself in determining satisfaction.

One of the core values of the independent living movement is empowerment. This is a term that is also used to describe the purpose of attendant care and other community-based services that support people living in the community. Some researchers have suggested, however, that while the term is frequently used, there is little agreement as to how it can be implemented in practice.

I. Summary: Major Findings and Lessons Learned

- The policy direction in Canada, as well as in many other countries, has changed from a philosophy of paternalism to the "open house" vision which respects and supports independence and responsibility. This is in keeping with the independent living philosophy and is incorporated in legislation in several jurisdictions.

- The evidence overwhelmingly indicates the capacity of individuals to live in community settings, given proper supports. Clients strongly favour community living, in particular the independent living models which give them control over their lives. Family members are also generally supportive of the relocation of their relatives with disabilities from institutional to community settings.

- Individual control and empowerment has been identified as one of the most important factors to the success of community services in facilitating skills development, community and social integration, consumer satisfaction and improvements in quality of life. Services based on independent living principles are more effective in this regard than traditional, professional-driven services.

- A number of evaluations have documented the effectiveness of direct funding, which gives individuals the funding and the control to select and to direct their own attendant care and other personal services.

- Advocacy, support and training services provided by independent living centres have been shown to be effective in enabling people to take control of their services and their lives.

- Effective community-based programs, in addition to personal support services, also need to take into account a broad range of needs including housing, transportation and support for families.

- Program design needs to consider the special needs of different populations, such as seniors, people with developmental disabilities and people who are deaf or hard of hearing. They should also take into account the setting, such as rural or urban, in which the service will be delivered.

- While principles of independent living are increasingly being incorporated into policies and program philosophies, the manner in which many agencies actually deliver services does not reflect these principles.

7. Implications for How and What to Evaluate in the Future

This chapter discusses lessons learned for the approach to evaluation itself, along with implications for future approaches to evaluation in the area of disability policy and programs. These lessons are based on our review of evaluations and related research that has been carried out - a somewhat different focus from the rest of this report.

A. Status of Current Information Base

This study has identified an impressive amount of evaluation information which *is* available, more than was expected when the study was initiated. Many of these studies are listed in the extensive bibliography to this report, which by no means represents a complete list. As this report has indicated, considerable information is available about many basic questions and issues — such as the capability of many people with disabilities to work given the appropriate supports and elimination of barriers. We know about the potential of many approaches, such as vocational rehabilitation and supported employment.

As the Federal Task Force on Disability Issues (1996) noted, there has been no lack of information, documented in a series of reports, about the need for action. But, as the Task Force said, "implementation of these visions and the recommendations has left a lot to be desired." This has significant implications for evaluation. Evaluation is needed to assess the extent to which policies and proposals are acted upon and to what effect. In addition to a monitoring function, evaluation can be very useful in aiding in program development and improvement. It can play a very useful role by identifying, as early as possible, where implementation runs into difficulties or takes a different course than anticipated, why, and what is needed, where applicable, to put things back on track.

Nevertheless, there is still a lot we do not know about what works or does not work, and why. Even when we know about the potential of an overall approach, such as supported employment or home care, there is not enough known about the effectiveness of specific programs or what makes a difference. Evaluation is frequently lacking, along with even basic data, such as who is being served and in what ways. Comparative evaluation examining the strengths and weaknesses of various potential approaches has been limited. Such information is critical for meaningful planning and priority setting, not to mention for delivery of services that really *will* be effective and make a difference.

As indicated in this text, lack of adequate consideration of interactions and relationships represent a major policy weakness. There has been insufficient coordination across jurisdictions, departments within the federal government, and even across program areas in the same department. Similarly, there has been limited evaluation exploring the interactions and linkages across different areas. This is a major field where more evaluation is needed.

Ongoing valuation will be needed to explore the effectiveness of emerging program and policy directions, as well as to provide guidance in the best ways of implementing new directions. For example, some exciting research is currently in progress, particularly exploring the effectiveness of initiatives in areas like direct funding, home care, consumer involvement, and deinstitutionalisation, in Canada and in the United States. With an aging population and more recognition of the key role of consumer control in a range of outcomes, these are all "growth" areas. The United States government has set up a number of research funding programs, sponsoring major evaluation and research studies in these and related areas. A number of evaluation activities are also under way exploring the impact of various aspects of ADA in the United states.

B. Evaluation Paradigms and Approaches

Participatory Approaches to Evaluation

There is a strong trend in the evaluation field towards greater emphasis on participatory and empowerment evaluation. This, for example, was a major theme at the 1995 International Evaluation Conference in Vancouver. A major lesson learned is the need for greater involvement of people with disabilities in research and evaluation of programs and policies that affect them. This is consistent with the current partnership approach to disability within the federal government, which has been highlighted by previous reviews (Mainstream, 1993; Federal Task Force, 1996).

There has been particularly strong condemnation within the disability community of the traditional research paradigm that leaves out the perspective of the subject in any consideration of the design, methods or results of research (see especially Oliver, 1990, 1992; Rioux and Bach, 1994: and Woodill, 1992). People with disabilities have expressed their resentment of others deciding what is best for them. They are just as upset by researchers and evaluators who decide research questions and approaches without involving them in the process.

The above writers, and others, have pointed out the major differences in the assumptions and questions used in research directed by professionals from those when consumers have been involved. When professionals determine the research questions, they tend to focus on problems with the individual. But when consumers help set the agenda for research, they identify questions related to the barriers and environmental factors that preclude participation, integration, productivity, socially accepted behaviours, and a host of other outcomes. These writers indicate that research needs to be based upon a socio-political model, one which takes into account the social and political context and factors in "our disabling society" (Rioux and Bach, 1994).

There is ample evidence documenting the practicality of involving consumers in evaluation (Byrnes, 1996; Cantrell and Walker, 1993; the Mainstream 1992 review). One of the themes at the 1996 International Association for the Scientific Study of Intellectual Disability conference in Helsinki was the active involvement of people with intellectual disabilities in research and

evaluation. There is evidence that the involvement of people with disabilities in the evaluation process can improve the quality and credibility of the evaluation, lead to more relevant and improved policies and programs, and result in improved outcomes for the participants themselves.

Practical Approaches to Evaluation Which Helps Programs Improve

A major theme in the evaluation field concerns the use or "utilization" of evaluation. There is little point in carrying out evaluation if it will not be used in some way. A focus on utilization requires evaluation to take a practical focus, providing timely, useful advice and guidance about how programs and policies can be improved. There is an extensive literature documenting the characteristics and features of evaluation most likely to result in use (Patton, 1997).

Evaluation most likely to result in action provides information about program effects and impacts, as well as implications for future directions, and is seen as credible and valid by key stakeholder groups. It needs to take into account the interests and concerns of various constituencies, ranging from senior executives and politicians in government to people with disabilities at the community level.

Evaluations that are most useful address questions such as: Are programs and policies indeed being implemented as intended? What are the reasons for these findings, and what are their implications for future directions? What are some of the barriers? How can these be overcome? When evaluation is implemented early, and is built into the program as much as possible, it can be used to provide feedback and guidance for programs.

A range of methods is needed, in particular qualitative, as well as quantitative evaluation data. Qualitative data can be especially valuable in providing an understanding of *why* given strategies are working or not. As Lutfiyya (1991) has noted, qualitative information can be used to "ground" findings in context, and to look at interactions and reasons. Given the importance of interrelationships and linkages that this report has identified, this seems particularly relevant. Qualitative methods also can provide a way of involving individuals in research and evaluation who are unable to answer questionnaires or to perform certain tasks, but who can still share their thoughts in other ways.

C. Success Indicators for Disability Policies and Programs

The literature indicates the need for a greater consensus on what are appropriate outcome measures for the evaluation of disability policies. Without agreement on at least the general goals of policies, it can be difficult or impossible to focus evaluation efforts or to identify appropriate measures of outcomes. As a result, evaluation findings may not be considered relevant or acceptable.

Two broad areas have emerged that may prove useful for thinking about the outcomes of disability policies: quality of life, and cost effectiveness. These are discussed below.

Quality of Life

The concept of quality of life is part of the public lexicon, with potential for considerable face validity. It can encompass other outcome measures frequently mentioned in the disability area, such as equality and social integration, consumer participation, and citizenship. It can be assessed through a variety of quantitative and qualitative measures. It can refer to living conditions of individuals, as well as of larger communities.

Quality of life can provide a way of thinking about outcomes from the perspective of the consumer, rather than in terms of what services are provided or what "experts" feel is appropriate. Quality of life now represents a major field of study in the disability area, with a strong and growing body of literature. It has been receiving extensive attention internationally. It is increasingly being viewed as an important, perhaps *the* key outcome indicator. For example, the title of a session at the forthcoming (May, 1997) American Association on Mental Retardation is entitled: "Quality of Life: Could It Be an Emerging International Disability Policy Concept for the 21st century?" The concept of quality of life is generic in nature, but considerable research in recent years has focused particularly on people with intellectual disabilities. Attention is now broadening to look at other population groups as well.

The concept of quality of life reflects two dimensions: objective indicators of life conditions, and individuals' subjective assessments about their life experiences (Borthwick-Duffy, 1996, Schalock, 1994). The literature indicates that both dimensions are important in assessing the impact of public policy.

A number of different approaches are being used in investigations of quality of life. They tend to share the above dimensions in one way or another. There is broad agreement that quality of life is a multi-dimensional construct. There have been various attempts to develop quantitative "quality of life" instruments. Some of the most extensive work in the area of assessment of quality of life has been by a University of Toronto group (Renwick, Brown and Raphael, 1994; Woodill, 1996).

The Accreditation Council (1993) has developed an approach to the evaluation of agencies serving people with disabilities that is consistent with the quality of life perspective. It has identified 30 outcome measures that can be used in shifting the perspective of social agencies from process to outcome and as a means of assessing impact and effectiveness. It has developed and is using a protocol for the accreditation of social agencies in the United States, which is now starting to be applied in Canada as well.

As Borthwick-Duffy (1996) indicated in a discussion about the evaluation and measurement of quality of life, there is a lack of consensus over basic conceptual issues (such as the legitimacy of subjective vs. objective assessments) as well as operational definitions and models. Despite various attempts to operationally define quality of life, "the fact remains that it is essentially a subjective construct that resists numerical scoring." *The* definitive measurement instrument probably has not yet been developed (although some may disagree). As Borthwick-Duffy indicated, it may be premature. Schalock (1996) indicates that quality of life is most useful as a

construct rather than as a score, and that it may be dangerous to attempt to quantify it at the present time.

Despite the promise of quality of life as a means of identifying outcomes from the perspective of the individual, it has been subject to criticisms from consumers (Byrnes, 1996; Pfeiffer, 1995). These concerns seem to be less with the concept *per se* than how it is operationalized and applied. For example, there is concern that quantitative ratings by "experts" which reduce quality of life to a number do not reflect reality or consumer perspectives about what is important to them. Approaches that have not provided for consumer participation have been criticized. Some measurement approaches are seen as overly intrusiveness. And while the multi-dimensional nature of quality of life and its measurement can be a strength, there is also a feeling that use of standardized instruments may not reflect issues germane to a particular situation. There is also a concern about how quality of life ratings can be used or misused. Pfeiffer (1995), for example, says that ratings of quality of life can be used to devalue people with disabilities whose ratings are too low, and even serve as grounds for euthanasia.

Cost Effectiveness

There is little disagreement, in principle, on the legitimacy of cost effectiveness as *one* measure of effectiveness. In a time where government programs are under increased scrutiny, value to taxpayers of public expenditures is receiving increased attention. Many people with disabilities, for example at hearings of the Federal Task Force, have also indicated their interest in seeing the limited amount of funding available for disability spent as effectively as possible. This report has cited evidence of cost effectiveness where available regarding the payback of various program approaches (of various employment strategies, for example).

Given that cost effectiveness is recognized as one key variable for assessing the impact of programs, it is striking that there has been so little conceptual attention paid to what this concept means in practice for assessing the costs and benefits of disability policies and programs. Because there has been only limited work (Federal Task Force, 1996; Perrin, 1991; Roeher, 1994) considering the costs of disability, including extraordinary costs to individuals and families, to government and society, there is limited understanding of what disability really costs. It is clear, from work done to date, that there can be a range of both direct and indirect costs. Costs can occur in one program area, with savings and benefits in another. Without consideration of the nature of costs resulting from disability, it is not possible to do meaningful cost-effectiveness analysis.

Policy decisions made in the absence of understanding of what it costs *not* to take action can be flawed. For example, the evaluation of the federal disability management pilot project found very limited understanding among senior managers about what it actually costs the government for employees who are off work due to disabilities.

Also, what is the best way to measure costs and benefits? What time frames are appropriate? The limitations of taking too short a time frame have been discussed. Perhaps more than with other target groups, initial expenditures in the disability area may be required where the

payback may not be until subsequent years. This can result in a reluctance to look at expenditures as investments. Nevertheless, as indicated above, there can be potential for major payback if an appropriate time frame is chosen. To give one example, a United States GAO report (1996i) has been cited indicating the potential for savings in Social Security Disability payments even if just a small number of people can be assisted in returning to work. Conversely, some evidence has been cited in this study to suggest that initial benefits or outcomes may not endure, at least under some conditions, and initial gains may be illusory.

Given the importance the federal government appears to be placing on cost effectiveness as a key evaluation outcome, it would appear that a priority area for additional research and evaluation attention would be in identifying effective and appropriate means of conceptualizing and assessing cost effectiveness. As noted above, a prerequisite to this is additional research to identify the full costs of disability, taking into account both direct and indirect costs and benefits.

Outcome Measures Tailored to Individual Circumstances

While one can set general parameters for considering outcomes, it is important that they not be applied in an overly rigid fashion. As this report indicates, there are many different types of programs serving people with widely ranging characteristics, needs and desires. One size cannot fit all. Evaluation designs need to be sensitive to differences and adapted to individual situations.

This paper has shown that employment is not an all-or-nothing matter. Many people are capable of some degree of work, for example on a part-time or episodic basis. Outcome indicators for the evaluation of employment programs may need to develop more specific indicators of employment status, to reflect the nature and characteristics of employment and to take into account the target audiences and specific program objectives.

While employment may be a goal for many people, evidence indicates that it is not appropriate for everyone, and it can be dangerous if it is used as an outcome measure where it may not be appropriate. As has been noted, there is strong potential for many CPP beneficiaries and recipients of other forms of disability income to be employed. But for others, this would not be a realistic outcome. Quality of life, including considerations such as independent living, community inclusion and integration, are also important goals. For many people, they are just as important as financial or economic goals.

D. Areas for Future Evaluation

Following are areas for which additional evaluation and research programs may be worthy of consideration. This is not meant as a complete list, but intended as a starting point for development of an evaluation and research strategy for disability. It should be noted that the appointment of the Minister of Human Resources Development as lead Minister for disability

issues provides an opportunity to develop a new research and evaluation strategy for disability that cuts across all government programs and departments.

Conceptual and Methodological Explorations

- Developmental work in defining and developing a consensus on appropriate and realistic outcome measures for the impact of policies and programs on people with disabilities.

- In particular, exploration of how the concept of quality of life can be used as a basis for evaluating the effectiveness of programs and services, building on the current Canadian and international work on quality of life.

- Exploration of the full costs of disability, including both direct and indirect costs and benefits, extraordinary costs borne by individuals and families, costs to government, to society and to others.

- Identification of considerations required for more meaningful cost effectiveness analysis in the disability area, taking into account considerations related to the identification and measurement of both costs and benefits.

- Longitudinal research in a variety of areas, in order to be able to identify long-term impacts, benefits and potential cost savings.

- Coordinated, multi-dimensional and multi-site research, such as is now under way in the United States and the United Kingdom.

- Use of evaluation models which provide for consumer involvement.

- Exploration of means of encouraging more attention to outcomes and evaluation by programs at all levels. This may involve the development of evaluation tools and resources to support more local level evaluation activity.

Policy and Program Directions

- Evaluations and research studies examining linkages and interrelationships across programs and across federal departments, as well as exploration of relationships with programs provided by other jurisdictions, considering areas where synergy is important as well as identifying gaps and overlaps.

- Evaluations identifying the extent to which the government response to the Federal Task Force has been implemented and the impact of these initiatives.

- Evaluation of the impact of the new EI Act on people with disabilities, taking into account the impact of the overall policy approach, as well as of services provided by

HRCCs directly, by third party agencies, and services provided through agreements with the provinces.

- Evaluation of the impact of the new Employment Equity legislation.

- Exploration of how other HRDC programs and policies are affecting people with disabilities.

- Research identifying the impact of the "new economy" on people with disabilities, as well as future challenges and opportunities.

- Greater use of demonstration or action research approaches which have non-token evaluation built into the design and budget, in order to test out new models of programming. CPP has been using this approach in exploring new ways of partnering with other programs with mutual beneficiaries.

Other Areas for Additional Evaluation and Research

- Tracking the size and characteristics of the disability population in Canada - for example, through reinstatement of the HALS survey or through alternative approaches, such as piggybacking on other survey vehicles or small-scale dedicated surveys with results reported on a more timely basis.

- Identifying characteristics of people served by various types of disability programs across Canada - for example, characteristics of people served by supported employment and independent living programs, as well as identification of which program approaches (alternative approaches to rehabilitation, the effectiveness of various approaches to barrier removal) work best for whom and under which circumstances.

- Evaluation identifying the extent to which the independent living model and a consumer perspective is being incorporated into the philosophies and operations of governmental and non-governmental programs and services.

Dissemination of Information about Findings and Implications from Evaluation Studies

A process is needed for information sharing about what is learned from evaluation and research findings, as well as identifying implications of this information for policy and practices. This study represents a good first step. Information sharing is most likely to be effective when it is planned as part of the evaluation design, and when the manner and style of reporting is tailored to the needs of specific stakeholder groups. There appears to be a need for information sharing among HRDC and other federal government staff, as well as with stakeholder groups.

Methods of information sharing used in other jurisdictions may be worthy of consideration. For example, the European Commission (1996) recently published a *European Guide of Good*

Practice Towards Equal Opportunities for Disabled People. What is particularly noteworthy about this guide is that it organizes best practices examples around principles in a number of different areas (work and preparation for employment, educational integration, social integration and independent living, functional rehabilitation). A participatory approach was used in the development of the principles.

The United States National Institute on Disability and Rehabilitation Research (NIDRR, 1995) has gone one step further. It has not only put a high priority on information dissemination ("to ensure that rehabilitation knowledge generated from projects and centres funded by NIDRR and others is utilized fully to improve the lives of individuals with disabilities and their families"). It is also establishing an infrastructure to share knowledge in a very practical way, through the creation of ten regional Disability and Business Technical Assistance Centers.

E. Summary: Major Findings and Lessons Learned

- More attention to the development of appropriate outcome measures for the evaluation of disability policy, and the development of a consensus about these, can enhance the credibility of future evaluation.

- There is particular potential for using the concept of quality of life as a primary outcome indicator.

- More research to identify the full costs associated with disability, and the costs and benefits of disability related policies and programs is a prerequisite to meaningful cost effectiveness analysis.

- Participatory models of evaluation, involving consumers in the process, can enhance the relevance of evaluation questions and develop credibility and support for findings. Use of a formative, practical, action-oriented approach to evaluation can aid in the use of evaluation in the design and improvement of policies and programs.

- The text discussed a number of areas where additional evaluation and research can be helpful.

- Mechanisms for dissemination of information about the implications of evaluation findings, both internally and externally to government, can aid in more effective use of evaluation.

8. Conclusion: Overall Lessons Learned

This report has identified a number of lessons learned under each of the specific topic areas discussed. Following is a summary of overall findings and lessons learned which cut across specific topic or program areas. A more detailed summary of both general and specific lessons learned is presented in the overview of this report.

Disability is likely to continue as a major public policy issue.

- The number of Canadians with disabilities (4.2 million in 1991, representing 15.5 per cent of the population) can be expected to increase as our society continues to age. Without effective interventions, this is likely to lead to increased pressure for services and to increased costs.

Disability issues and topics are inter-related.

- There is substantial evidence, from Canada and abroad, indicating relationships and linkages across seemingly separate areas such as: employment, transportation, housing and living arrangements, personal support, income support, access to rehabilitation and training, and others. This in turn leads to related findings or lessons from the evaluation literature.

- A coordinated, holistic approach across federal government departments and with other jurisdictions is needed to address the complexity of issues and their linkages and to provide for coordination of policies and approaches. Without a coordinated approach, the result is frequently fragmented, with inconsistencies, overlaps, and gaps within and across jurisdictions.

- The all-or-nothing approach inherent in eligibility requirements of some income security programs, which labels people as either fully employable or unemployable, acts as a major disincentive to employment and reinforces the welfare trap.

- Environmental barriers have been found to be a greater impediment to employment and participation in society than functional limitations. Barrier removal, through legislative approaches, the availably of workplace accommodations, and through other means, has been identified as the key to the social integration of people with disabilities.

A variety of approaches that facilitate the participation of people with disabilities in employment and in independent living have proven cost effective in reducing the massive direct and indirect costs of disability.

- The text of this report has identified the cost effectiveness of a number of interventions, such as disability management, workplace accommodations and supported employment, as well as measures intended to permit independent living in the community.

Many approaches that permit the participation of people with disabilities can be low cost, but require the involvement of different sectors in society, frequently on a partnership basis.

- Most workplace accommodations are low in cost and many, such as modifications to the work task or rearrangement of the work site, require no additional expenditures. Costs are also minimal when accessibility is built into the design of facilities and generic programs, as opposed to retrofitting.

- Attitudinal barriers and lack of information about the capabilities of people with disabilities have been found to be among the biggest obstacles to independent living and to employment. These can result in systemic discrimination and the lack of opportunities for people with disabilities.

- The United states (ADA) experience has demonstrated that changes in attitudes can effectively follow changes in behaviour when standards and expectations are clearly set out. The Canadian approach has not been as effective: vague standards and lack of effective enforcement mechanisms often force individuals to litigate to prove discrimination, resulting in an adversarial environment.

- The provision of clear standards and the availability of technical information and support has led in the United States to increased compliance by employers and private and public facilities with the accessibility provisions of ADA.

Mainstreaming is necessary to ensure equality and to achieve the integration of people with disabilities.

- There is ample evidence that there is higher individual satisfaction and quality of life when individuals are able to make use of generic programs and services in the community, rather than having to use special or segregated programs and facilities.

Direct involvement of individuals with disabilities with programs, services and policies affecting them, as well as with evaluations, has been found to be associated with increased satisfaction and support, higher levels of functioning and greater success at community integration.

- Direct funding to enable people with disabilities to purchase and direct their own attendant care and personal support services has been shown to be more effective and to result in greater satisfaction than traditional approaches, where professionals decide on needs without involving the individual.

- Direct involvement of people with disabilities in policy reviews, such as with Mainstream 1992 Review and the 1996 Federal Task Force on Disability Issues, has demonstrated how this can lead to the development of a consensus and support for the directions taken.

- Similarly, there is evidence that the involvement of people with disabilities in evaluation studies can improve the quality and credibility of the evaluation, and lead to more relevant and improved policies and programs -- and also lead to improved functioning of the individuals involved.

There is insufficient information about the full costs of disability, which can lead to inappropriate and costly decisions.

- More research is needed to clearly identify the full range of direct and indirect costs associated with disability. This in turn will permit more meaningful determination of the cost-effectiveness of various programs and measures.

- Benefits from program measures and expenditures may accrue to different cost centres than those incurring the costs. This is one reason why, in spite of an impressive return-on-investment, disability management interventions have sometimes failed to obtain the support of senior management and human resources officials.

Not enough is known about the reasons for the effectiveness of various types of approaches intended to aid in the community integration of people with disabilities.

- There is a need for more evaluation at various levels, ranging from the individual project level to consideration of the inter-relationships of programs cutting across different program areas and jurisdictions, in order to identify which approaches are most effective under given circumstances and to better target programs where they can be as effective as possible.

- There is a particular need for evaluation that identifies the reasons for effectiveness and facilitates learning from experience.

Solid data about the disability population in Canada is needed for effective planning, policy development and evaluation.

- HALS has proven very useful in many different respects. It was discontinued, however, by Statistics Canada, after the 1991 survey. Lack of basic descriptive data can result in policy decisions being made in a vacuum. There appears to be an need for either the reinstatement of HALS, or the creation of an alternative means for identifying the size and characteristics of the disability population in Canada, such as piggybacking questions about disability on other survey vehicles.

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[1]JAN is a United States-based organization which has been contracted to provide information services about accommodation, using a toll-free telephone line within Canada.

[2]We became aware of this volume only very recently and have been unable to review it in detail for the present study. However, it appears to contain very important research relating to the diversity of persons with disabilities and to health services and related in-kind benefits, particularly the eligibility of persons with disabilities who are working to retain necessary health and disability-related services.